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Minimizing the Impact of Disease While Maximizing Quality of Life: An Exploration of Resilience in Head and Neck Cancer Survivors

Chelsea A. MacDonald
The University of Western Ontario

Supervisor
Dr. Philip Doyle
The University of Western Ontario

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ABSTRACT

Introduction: Individuals with head and neck cancer (HNCa) face myriad biopsychosocial challenges. Even after treatment completion, these challenges may continue to cause diminished quality of life (QoL). Resilience may serve to minimize the impact of HNCa and, thus, maximize QoL. The purpose of this study was to identify resilience in HNCa survivors and explore its potential relationship with QoL.

Methods: Thirty-one HNCa survivors completed three validated, self-report questionnaires pertaining to the collection of resilience and QoL data. Descriptive, correlational, and observational analyses were performed.

Results: Resilience was identified in the HNCa survivors and a positive correlation was found between resilience and QoL.

Conclusions: Data suggest that resilience may buffer the influence of HNCa on QoL. Screening for low levels of resilience may facilitate the identification of those who are vulnerable to the impact of HNCa. Interventions that foster resilience may serve to ameliorate the challenges of HNCa and improve QoL.

Keywords: resilience, quality of life, survivorship, disablement, head and neck cancer

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CHAPTER 1

Introduction and Review of Literature

Introduction

> Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, 1978, p. 3)

The diagnosis of head and neck cancer (HNCa) acts as a vehicle through which an individual is permitted to cross the border from the kingdom of the well to the kingdom of the sick. Citizens of the kingdom of the sick are initiated by the disabling physical, psychological, and social consequences of HNCa and its treatment. Owing to medical advancements in oncological treatment, an increasing number of individuals residing in the kingdom of the sick secondary to a diagnosis of HNCa are commonly issued a third passport. This additional passport grants them citizenship to a new kingdom that Frank (1995) refers to as the "remission society" (p. 8). For those who have completed treatment for HNCa, gaining citizenship to the remission society implies that individuals are no longer sick, but simultaneously remain marked by their past experience of sickness (Frank, 1995).

Unfortunately, citizenship in the remission society comes at a great cost. Despite delivering a biological cure for cancer, advanced medical treatment often leaves members of the remission society who are deemed "cancer free" at a great distance away from the kingdom of the well. It follows that something must be done to provide HNCa survivors with the direction they need to navigate the complex path back to the kingdom of the well. In essence, before

survivors leave the kingdom of the sick, they should be equipped with a map to guide them through the process of positive adaptation to their experience with HNCa. If a proactive stance is adopted in oncological care to help those who will become cancer survivors rebound from their time spent in the kingdom of the sick, individuals may find their way back to the kingdom of the well more effectively. As part of this journey, *resilience* may serve as the proverbial map that aids HNCa survivors' navigation back to the kingdom of the well. Intrinsically, resilience may enable HNCa survivors who are citizens of the remission society to bridge the potentially expansive gap between Sontag's two metaphoric kingdoms.

Regrettably, the distance between the kingdoms of the sick and well may become expansive as a result of significant detriments to quality of life (QoL) secondary to HNCa and its treatment. Poor QoL often denotes that a significant gap exists between an individual's ideal functional status and current level of functioning (Semple, Sullivan, Dunwoody, & Kernohan, 2004). For individuals who have received a diagnosis of HNCa, this gap may be particularly expansive due to the profound biopsychosocial challenges they may experience related to speech, swallowing, social interaction, pain, and depression. Consideration of the potential gap between an individual's current and ideal functional status may promote the notion that survival alone is an insufficient indicator of the effectiveness of cancer treatment and, thus, shift the focus of care to providing individuals with the maximum *quality of life*, in addition to providing individuals with the maximum *quantity of life* (Semple et al., 2004).

Although it can be expected that one's QoL is negatively influenced by HNCa, no simple or linear relationship exists between the experience of the disease and dimensions of QoL (Lawford & Eiser, 2001). Individuals' capacity to rebound from their experience of surviving HNCa and their appraisal of its overall impact, will idiosyncratically influence their perceived

QoL (Lawford & Eiser, 2001). As such, substantial evidence exists to suggest that individuals with similar cancer diagnoses and treatment statuses have divergent levels of perceived QoL (Huber, Sillick, & Skarakis-Doyle, 2010). It is suggested that resilience may act as a central factor to explain differing perceptions of QoL despite parallel circumstances (Tian & Hong, 2014). For instance, two individuals with comparable experiences of HNCa may vary substantially in their perceived QoL as a function of the role played by resilience in their subjective disablement experiences. In essence, resilience may substantially influence how one fares following the completion of treatment for HNCa. Moreover, resilience may play a role in buffering the influence of the adverse experience of HNCa and its treatment on survivors' QoL. The identification of resilience in individuals who have completed treatment for HNCa may initiate acknowledgement of its value in acting as a potential protective process that may reduce the impact of HNCa on one's QoL and ultimately, bridge the gap between the kingdom of the sick and the kingdom of the well.

In the sections to follow, a comprehensive introduction related to HNCa will be initially presented. This will be followed by a presentation of the multifaceted concept of survivorship. Introductory information pertaining to the constructs of resilience and QoL will subsequently be provided. Finally, the statement of problem and rationale for the present study will be delineated. Owing to the expansive array of challenges secondary to the experience of HNCa and its treatment, the process through which HNCa survivors navigate the complex path back to wellness is of particular interest. As such, the investigation of resilience in HNCa survivors may elucidate its role in ameliorating the impact of HNCa and its treatment on survivors' QoL.

Head and Neck Cancer

HNCa is the sixth most common malignancy in the world, with approximately 650,000 new cases diagnosed annually (Howren, Christensen, Karnell, & Funk, 2012; Pai & Westra, 2009). HNCa refers to malignant tumours that originate from the epithelial lining of the paranasal sinuses, nasal cavity, oral cavity, salivary glands, pharynx, and larynx (Howren et al., 2012; Murphy, Ridner, Wells, & Dietrich, 2007). HNCa also includes tumours arising from the craniofacial bones, soft tissues, skin, and neurovascular structures of the head and neck region (Shah & Lydiatt, 1995; Pai & Westra, 2009). Malignancies found in the thyroid gland, parathyroid gland, and the parapharyngeal space also fall under the extensive classification of HNCa (Shah & Lydiatt, 1995). Head and neck cancers are predominantly squamous cell carcinomas of the mucosal surfaces in the upper aerodigestive tract (Campisi & Giovannelli, 2009). Melanomas, sarcomas, lymphomas, and adenocarcinomas are other less common types of head and neck tumours (Semple et al., 2004).

Staging of head and neck cancer. The American Joint Committee on Cancer Tumour-Node-Metastasis (TNM) staging system stipulates the staging criteria for HNCa (Vokes, 2012). The TNM staging system categorizes malignancies based on their anatomic site and scope or extent of disease (McQuade, Gunn, William, & Kies, 2016). For HNCa, the primary subsite of the malignancy dictates the intricate parameters for both clinical and pathological staging of the primary tumour (McQuade et al., 2016). The "T" classification describes the size of the primary tumour. Vokes (2012) explained that "in general, primary tumours are classified as T_1 to T_3 by increasing size, whereas T_4 usually represents invasion of another structure such as bone, muscle, or root of tongue" (Clinical Presentation and Differential Diagnosis, para. 7). The extent of lymph node involvement is represented by the "N" classification. To categorize lymph node

involvement, staging is based on the location of the involved lymph nodes (ipsilateral versus contralateral to the primary tumour), as well as the size and number of nodes involved (Vokes, 2012). The degree of metastases, or spread of the cancer to other parts of the body, is described by the "M" classification. For all HNCa sites, excluding the nasopharynx, the TNM staging system has uniform criteria for making categorizations based on lymph node (N) involvement and potential distant metastases (M) of the tumour (McQuade et al., 2016). Table 1 summarizes common TNM staging for squamous cell carcinomas in the head and neck region, with the exception of nasopharyngeal carcinomas.

Table 1

*Common TNM Staging for Head and Neck Squamous Cell Carcinomas (Except Nasopharyngeal Carcinoma) **

Classification	Characteristic
T_1	Tumour ≤ 2cm in greatest dimension
T_2	Tumour > 2cm but < 4cm in greatest dimension
T_3	Tumour > 4cm in greatest dimension
T_4	Tumour invades adjacent structure
N_0	No regional LNs
N_1	Single ipsilateral LN, ≤ 3cm
N_{2a}	Single ipsilateral LN, > 3cm but < 6cm
N_{2b}	Multiple ipsilateral LNs, none > 6cm
N_{2c}	Bilateral or contralateral LN, none > 6cm
N_3	Any LN > 6cm
M_0	No distant metastasis
M_1	Distant metastasis

*LN = lymph node.

Note. From Correction, by S. Marur and A. A. Forastiere, 2008, *Mayo Clinic Proceedings*, *83*(5), p. 604. Reprinted with permission.

Presentation of head and neck cancer. The presentation of HNCa varies according to the stage and site of the primary tumour (Vokes, 2012). In general, early-stage head and neck malignancies infrequently cause symptoms, but may manifest vague and minimal somatic indications (Marur & Forastiere, 2008). Tumours that arise from the paranasal sinuses, nasal cavity, and nasopharynx generally manifest in sinusitis (inflammation of a nasal sinus), nasal air way obstruction, otitis media (inflammation of the middle ear), and epistaxis (bleeding from the nose) (Marur & Forastiere, 2008; Vokes, 2012). Additionally, advanced nasopharyngeal

carcinomas may also present with cranial nerve palsies (Marur & Forastiere, 2008). Painful lesions and non-healing ulcers or sores are typical presentations of oral cavity malignancies (Vokes, 2012). When tumours arise from structures that comprise the oropharynx, patients may present with reduced mobility of the tongue, sore throat, dysphagia (impaired swallowing) or odynophagia (painful swallowing), changes in voice, speech, and otalgia (ear ache) (Marur & Forastiere, 2008; Vokes, 2012).

In later stages of cancers occurring in the hypopharynx, sore throat, hoarseness, dysphagia, cervical adenopathy (enlargement of lymph nodes in the neck), and otalgia are common symptoms (Marur & Forastiere, 2008; Vokes, 2012). Individuals with laryngeal cancer may also present with hoarseness, however, the disease progression of cancers of the larynx may vary with subsite (Marur & Forastiere, 2008; Vokes, 2012). For instance, glottic cancers (cancers of the vocal folds) are often diagnosed early in the course of the disease and have higher success rates of curative treatment (Marur & Forastiere, 2008). Conversely, supraglottic carcinomas (lesions superior to the vocal folds) are typically diagnosed at later stages of the disease upon discovery of a neck mass (Marur & Forastiere, 2008).

Etiology of head and neck cancer. The most common etiological factors of HNCa are tobacco and alcohol (Marur & Forastiere, 2008). These substances contribute independently to the development of HNCa, however, they are often used in combination and also act synergistically to produce a multiplicative impact on carcinogenesis (Howren et al., 2012; Muscat & Wynder, 1992; Rodriguez et al., 2003; Vokes, 2012; Wynder & Stellman, 1977). The carcinogenic effect of tobacco is a result of the consumption of nicotine and polycyclic aromatic hydrocarbons (Marur & Forastiere, 2008; Pai & Westra, 2009). Tobacco smoke effects the tissues of the aerodigestive tract through the conversion of the carcinogenic compounds into

reactive metabolites that interact with DNA through the action of oxidative enzymes (Vargas-Ferreira et al., 2012). The genotoxic effect of the carcinogenic chemicals found in tobacco also increases the risk of developing HNCa when individuals are subjected to passive smoking (Pai & Westra, 2009).

Alcohol acts as a chemical solvent that heightens the risks associated with smoking by "enhancing and prolonging mucosal exposure to the carcinogens present in tobacco smoke" (Pai & Westra, 2009, p. 51). Extended exposure to the carcinogenic chemicals found in tobacco enables the passage of the carcinogens into the cells of the mucous membrane of the upper aerodigestive tract (Lee et al., 2007). The carcinogenic influence of alcohol and tobacco consumption can be observed at the level of the squamous cells that line the mucous membranes in the form of substantial damage to the DNA contained in these cells (Scully, Field, & Tanzawa, 2000). For instance, squamous cell carcinoma in the head and neck region commonly occurs as a result of extensive molecular damage to the DNA and consequent cell dysregulation that occurs secondary to "disruption of cell signaling, the cell growth cycle, or mechanisms to repair cell damage or eliminate dysfunctional cells" (Scully et al., 2000). The progressive assemblage of DNA damage ultimately leads to autonomous division of the squamous cells that eventually results in carcinoma (Scully et al., 2000). The process of alcohol-related carcinogenesis in the head and neck region is also attributable to the metabolism of ethanol into the metabolite acetaldehyde (Seitz & Stickel, 2007). Acetaldehyde binds to segments of DNA to form DNA adducts that hinder DNA synthesis and repair and are commonly the beginning of carcinogenesis (Pai & Westra, 2009; Seitz & Stickel, 2007).

Traditionally, smoking trends have mirrored the rate of oropharyngeal cancer (Pai & Westra, 2009). However, over the span of the last 20 years the incidence of oropharyngeal cancer

has increased substantially without any corresponding increase in smoking trends (Pai & Westra, 2009; Walden & Aygun, 2013). Subtypes of the Human Papilloma Virus (HPV) are now recognized as being the reason for the divergence between oropharyngeal cancer trends and smoking trends. HPV is also responsible for shifting the demographics of oropharyngeal carcinomas towards younger non-smoking individuals (Marur & Forastiere, 2008; Pai & Westra, 2009). Fortunately, HPV positive oropharyngeal malignancies have a more favourable prognosis and are associated with increased survival since HPV positive tumours have heightened sensitivity and responsivity to radiation and chemotherapy (Howren et al., 2012; Marur, D'Souza, Westra, & Forastiere, 2010; Vokes, 2012).

The Epstein-Barr virus is another common viral etiological factor of HNCa (Howren et al., 2012; Marur & Forastiere, 2008). While HPV is commonly linked to oropharyngeal cancers, the Epstein-Barr virus is recognized as being a causative factor in the development of nasopharyngeal carcinomas (Howren et al., 2012; Vokes, 2012). It is also worth noting that other etiological factors of HNCa include diet; oral hygiene; carcinogen exposure to nickel, chromium, radium, mustard gas, and asbestos; infectious agents; marijuana use; family history and pre-existing health conditions (Marur & Forastiere, 2008; Pai & Westra, 2009). Regardless of etiology, the treatment modality acts as an additional factor that further effects an individual's experience with HNCa.

Treatment of Head and Neck Cancer

The treatment for HNCa and the associated treatment morbidities that may affect physical, psychological, and social functioning have the potential to substantially influence an individual's journey through HNCa and intensify the experience of living with a life-threatening disease (Johansson, Ryden, & Finizia, 2008). Treatment for the management of HNCa

commonly includes surgery, radiation therapy, chemotherapy, or multimodal approaches (Marur & Forastiere, 2016). Surgery alone may be sufficient to remove an early-stage tumour, however, more aggressive surgical procedures may be utilized when organ-preserving therapies that seek to retain anatomic structure of the affected site, are deemed insufficient as the sole treatment modality (Marur & Forastiere, 2016). Additionally, salvage surgery may be done when radiation or chemotherapy fail (Argiris, Karamouzis, Raben, & Ferris, 2008). Radiation therapy may be used in isolation, adjunctively with surgery, or concurrently with chemotherapy (Marur & Forastiere, 2016). Chemotherapy is commonly used as part of initial multimodal treatment of HNCa, but generally only as adjuvant treatment (Marur & Forastiere, 2016).

Complete tumour eradication is the primary goal of treatment, however, the preservation of structure and function, minimization of treatment sequelae, and maximization of QoL should also be central to treatment choice (Shah & Lydiatt, 1995). Nonetheless, the TNM staging of the tumour provides foundational information that guides the treatment decision process. For instance, surgery or radiation are generally deemed to be the optimal singular treatment modality for early-stage tumours staged as T_1 or T_2 that do not involve nearby lymph nodes or distant metastases (Marur & Forastiere, 2008; McQuade et al., 2016; Vokes, 2012). A multimodal treatment approach that includes concomitant chemoradiation therapy (CRT) is standard for intermediate tumours staged as T_2 or T_3 with N_0 to N_1 lymph node involvement that are either unresectable or resectable, but require further treatment postoperatively (Marur & Forastiere, 2008; McQuade et al., 2016; Vokes, 2012). Optimal treatment plans for advanced HNCa, staged as T_3 or T_4, with lymph node involvement characterized as N_2 or N_3, generally consist of one of the following three multimodal treatment strategies:

> (1) induction, also known as neoadjuvant therapy, with chemotherapy given before surgery or radiation; (2) concomitant chemoradiation, with chemotherapy given simultaneously with radiation to enhance its effect; [or] (3) adjuvant therapy, where chemotherapy is given after surgery or radiation in an effort to decrease microscopic metastatic disease burden. (McQuade et al., 2016, Combined-Modality Therapy section, para. 1)

Consideration of the TNM staging must also be balanced with consideration of the anatomical location of the tumour and associated risk of lymphatic system involvement in order to determine the optimal treatment modality (Shah & Lydiatt, 1995; Walden & Aygun, 2013). For instance, when the primary tumour occurs in the larynx, radiation therapy is often the selected treatment method so that the structure of the larynx remains intact and voice and swallowing functions can be preserved (Walden & Aygun, 2013; Vokes, 2012; Shah & Lydiatt, 1995). Conversely, surgery is often deemed the optimal treatment modality when the primary tumour arises out of the oral cavity so that long-term side effects of radiation including xerstomia (sensation of dry mouth) and dental decay are prevented (Vokes, 2012). Depending on the amount of involvement of the base of tongue, constrictor muscles, and epiglottis, prevention of aspiration and conservation of the swallowing function and speech are central considerations in treatment decisions for tumours that occur in the oropharynx or hypopharynx (Walden & Aygun, 2013). Accordingly, in an attempt to preserve the structure of the pharynx, radiation is often the preferred treatment for nasopharyngeal and oropharyngeal tumours (Shah & Lydiatt, 1995). Since nasal cavity or paranasal sinus carcinomas rarely present at an early stage, surgery is generally the definitive treatment option for such tumours (Shah & Lydiatt, 1995).

Regardless of the treatment modality selected, the management of HNCa carries a significant risk to individuals' functioning in the pursuit of achieving a biological cure (McQuade et al., 2016). Therefore, the grueling effects of the treatment associated with HNCa often add substantial burden to an individual's experience with cancer (Pauloski, 2008) and subjects the individual to profound disablement. Disablement can be conceptualized as the influence of chronic and acute health conditions on an individual's functioning at intrapersonal, interpersonal and environmental levels (Jette, 2006). From a biopsychosocial perspective, an individual's experience of disablement can be considered to be an outcome of the dynamic interaction of biological, personal, and social forces (Jette, 2006). As such, not only does HNCa cause substantial disablement, but surgery, radiation therapy, and chemotherapy commonly have a significant influence on HNCa survivors' process of recovery owing to the consequential decrements to multiple domains of functioning (DeBoer, McCormick, Pruyn, Ryckman, & Van Den Borne, 1999).

Even after treatment for HNCa has concluded, the effects of treatment continue to impact the individual in domains of physical, psychological, and social functioning. Owing to the complexity of the anatomical location and necessity of the pathological function of the region affected by HNCa, surgery, radiation therapy, and chemotherapy have the potential to result in substantial physical, psychological, and social treatment sequelae that are highly interrelated (Newell, Sanson-Fisher, Girgis, & Ackland, 1999).

Treatment sequelae: Physical domain of functioning. Significant treatment sequelae may occur secondary to **s**urgery, radiation therapy, and/or chemotherapy that impair an individual's functioning in the physical domain. Radical surgery for HNCa often significantly modifies the structure and function of organs which may lead to disfigurement or loss of speech

and swallowing function (McQuade et al., 2016). Although uncommon, postoperative complications associated with surgery for HNCa may include infection, fistula (an atypical fusion between tubal organs, such as those in the head and neck region), wound dehiscence (the rupture of a surgical wound along the sutures), haematoma (a pooling of blood outside the blood vessels), seroma (a collection of fluid in a tissue or an organ), and flap necrosis (death of tissue that has been relocated from one location of the body to another) (Derks, De Leeuw, Hordijk, & Winnubst, 2003).

Nevertheless, nonsurgical treatment modalities also have the potential to cause harm to a patient's physical functional status (McQuade et al., 2016). Although radiation therapy is primarily prescribed for curative purposes, this modality has the perceived benefit of preserving structures of the head and neck (Pauloski, 2008). It could be assumed that if macroscopic structure is preserved, the function of the exposed anatomical region will also be maintained. In actuality, radiation therapy for HNCa is prescribed for tumour eradication, however, radiation therapy commonly results in substantial negative consequences in relation to physical functioning that may nullify the benefits of organ preservation accomplished (Adelstein et al., 2000). The disabling side effects of radiation therapy are a result of damage to soft tissue structures that are within the radiation treatment volume, including tendons, ligaments, fascia, muscles, and fibrous and connective tissues (Murphy & Gilbert, 2009). In response to the inflicted damage, an inflammatory reaction in this anatomical region is triggered, which in turn causes radiation-induced fibrosis (Murphy & Gilbert, 2009). Fibrosis in the irradiated tissues is demarcated by a diffuse scarring process that ultimately causes the tissue to become less elastic (Pauloski, 2008). Additionally, because radiotherapy uses reactive oxygen species to destroy

cancerous cells, chronic oxidative stress causes the perpetuation of tissue damage that results in ongoing side-effects long after the completion of the radiotherapy (Murphy & Gilbert, 2009).

Howren et al. (2012) explained that during the course of radiotherapy, "the importance of pain as a patient-reported outcome cannot be overstated as at least half of [HNCa] patients will experience some degree of pain" (p. 15). Pain is a very common and significant side-effect associated with radiotherapy for the treatment of HNCa due to the structural damage to the oral mucosa that results in mucositis (Pauloski, 2008). Mucositis is characterized by ulceration of the mucous membranes that line the tissues in the field of radiation and is caused by the consequential increase in levels of reactive oxygen species utilized by the radiotherapy to destroy the cancerous cells (Pauloski, 2008). Functionally, the pain and ulceration of mucositis impairs chewing, swallowing, and manipulation of food in the mouth and may lead to dehydration, malnutrition, and weight loss (Vokes, 2012). As a result of radiation therapy, severe ulceration associated with mucositis, in conjunction with an immobile larynx as a result of the radiation-induced fibrosis, may lead to the narrowing or complete closure of the pharynx or esophagus, referred to as stricture (Pauloski, 2008). Stricture results when the anterior and posterior mucosal surfaces heal together which causes adhesion and the ultimate closure of the pharynx or esophagus (Pauloski, 2008). Stricture limits the passage of liquid and food which has a significant impact on swallowing function and the risk of malnutrition and weight loss (Pauloski, 2008).

Dysphagia refers to the disruption of the swallowing function that causes difficulty with the transport of solids or liquids from the mouth to the stomach and may be the result of fibrosis and stricture caused by radiation for HNCa (Gaziano, 2002). Coincidentally, damage to the salivary glands caused by radiotherapy causes a substantial decrease in salivary flow, referred to

as hypofunction of the salivary glands (Pauloski, 2008). Thus, an individual's experience with dysphagia is commonly augmented by the perception of dryness in the oral cavity, referred to as xerostomia, which is commonly associated with salivary gland hypofunction (Pauloski, 2008).

Chemotherapy is also associated with a host of disabling side-effects. A common treatment sequela of chemotherapy is myelosuppression, which refers to a decrease in bone marrow activity that causes a decline in red blood cells, white blood cells, and/or platelets, (Vokes, 2012). Myelosuppression can result in fatigue, dizziness, and the body's diminished ability to fight infection and disease (Zangemeister-Wittke & Simon, 2012). Kidney damage (nephrotoxicity) may be a further complication of chemotherapy (Vokes, 2012). Individuals may also experience nausea, vomiting, mucositis, and dysgeusia (alteration of the perception of taste), all of which make maintaining adequate nutrition a difficult task (Vokes, 2012). To further complicate matters of nutrition, chemotherapy may also result in dysphagia, xerostomia, fibrosis, and pharyngeal scarring that may lead to feeding-tube dependence (Marur et al., 2010).

Treatment sequelae: Psychological domain of functioning. The extensive array of physical sequelae of HNCa treatment is paralleled by substantial distress characterized by marked psychological dysfunction (Bornbaum, Doyle, Skarakis-Doyle, & Theurer, 2013; Bornbaum et al., 2012; Semple et al., 2004). The National Comprehensive Cancer Network Distress Management Panel defines distress in the context of an individual's experience with cancer as:

> a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and

> fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis. (as cited in Carlson & Bultz, 2004, p. 838)

HNCa patients' experience of distress, specifically depression, either as clinical depressive disorder or subclinical symptomology, is notable since the prevalence of depression is higher in individuals with HNCa than in individuals with other cancer diagnoses (Howren et al., 2012). This is understandable since the experience of distress is associated with the physical and social sequelae of treatment that are particularly grueling for individuals with HNCa. For instance, a positive correlation exists between high levels of distress and intense experiences of physical sequelae, such as pain, fatigue, and nausea, and social sequelae, such as social isolation and relationship disruption (Aaronson, 1991; Bjordal & Kaasa, 1995; Kugaya et al., 2000; Newell et al., 1999).

It is worth noting that transient negative emotions are a natural and common response to an adverse life event such as the experience of HNCa and its treatment (McDonough, Boyd, Varvares, & Maves, 1996). In other words, depressive feelings are a normal and foreseeable element of the HNCa experience. However, in a select group of individuals with HNCa, the depressive feelings may persist to a degree that substantially inhibits coping for a period of time that is considered extensive enough to determine that the expected negative feelings have transitioned to dysfunctional depressive symptoms (Haman, 2008; McDonough et al., 1996). When normal negative feelings become dysfunctional, the underlying cause of the depression must be determined and addressed in order to avoid serious potential implications of the experience of depression (McDonough et al., 1996).

One potential implication is that the experience of depression secondary to HNCa and its treatment substantially impairs an individual's ability to return to pre-diagnosis functioning in

domains of speech, eating, and social interactions (Howren et al., 2012). Depression may also impact a HNCa patient's immune response, habits of self-care, treatment compliance, and risk of malnutrition (Howren et al., 2012). Furthermore, it is suggested that depression and psychological dysfunction that result from the disabling physical and social side-effects of HNCa and its treatment are probable contributing factors for the majority of suicides in those with HNCa (Kendal, 2007). Concerningly, the incidence of suicide is highest in individuals who have received a diagnosis of HNCa compared to individuals who have received other cancer diagnoses (Bjordal & Kaasa, 1995; Kendal, 2007; Misono, Weiss, Fann, Redman, & Yueh, 2008). This high suicide rate is telling of the significant burden of HNCa and its treatment.

Due to the anatomical location of the structures impacted by HNCa and its treatment, visible disfigurement is another common treatment outcome that has the potential to contribute to psychological dysfunction. It is almost impossible for many individuals who have received treatment for HNCa to conceal the signs of the disease and its treatment (Howren et al., 2012; Nash, 2014; Semple et al., 2004). The unconcealable signs of HNCa treatments often cause individuals to experience challenges related to intimacy, making friends, and acquiring jobs (Howren et al., 2012; Semple et al., 2004). Visible disfigurement may also augment distress, depression, and social anxiety and isolation (Howren et al., 2012; Semple et al., 2004). Additionally, permanent disfigurement often has noteworthy implications for the individual's body-image, self-esteem, and self-concept (Cohen et al., 2015; Gritz et al., 1999; Murphy et al., 2007; Nash, 2014).

The physical treatment sequelae of HNCa that influence an individual's psychological functioning are not only visually apparent, but also auditorily apparent (Doyle, 2005). HNCa is unique in that it is the only form of cancer that alters the "structural integrity to effectively

communicate, or in some instances render the individual unable to verbally communicate at all" (Doyle, 2005, p. 11). As a result of the extreme visibility of HNCa and its treatment, those with HNCa may be exposed to unsolicited and untoward staring and comments (Semple et al., 2004). Correspondingly, individuals with HNCa are at a heightened risk of feeling stigmatized in society (Howren et al., 2012; Semple et al., 2004). Goffman explained that "stigmatizing conditions, whether real or perceived, cannot be overlooked because they threaten the individual's judgment of self, which might then pose a risk to relationships within the individual's own social milieu" (as cited in Doyle, 2005, p. 11).

Treatment sequelae: Social domain of functioning. The functional impairment associated with HNCa and its treatment also exerts a wide-ranging influence on the individual's social functioning. Several of the physical treatment sequelae of HNCa treatments, including dysphagia, xerostomia, dysgeusia, and mucositis, can impair individuals' ability to engage in shared meal times in social settings which can lead to social isolation (Pateman, Ford, Batsone, & Farah, 2015; Threats, 2007). The consequential restricted social involvement may be an outcome of the perceived indignity of the restricted food choices necessitated by swallowing and chewing dysfunction that result from the aforementioned physical sequelae of HNCa treatment (Patterson, McColl, Wilson, Carding & Rapley, 2015). Individuals may be influenced to select social engagements carefully to avoid the added burden of social tension or pressure that could result from a clash between the challenges of dysphagia and socially constructed norms, which can lead to further social isolation (Nund et al., 2014).

Furthermore, socially constructed eating and drinking customs are associated with significant symbolic value (DeRenzo, 1997). The social customs surrounding eating and drinking influence food choices, acceptable methods of consumption and the accepted timing of meals

(DeRenzo, 1997). Unfortunately, individuals who have undergone treatment for HNCa may no longer be able to conform to these social customs of eating. The added perception of not conforming to social norms can augment the burden of the physical HNCa treatment sequelae and concomitant social isolation. An individual's experience with dysphagia, xerostomia, dysgeusia, and mucositis can promote the attribution of a strictly nutritional and survival based meaning to food that may clash with social customs of food that have minimal connection to nutritional factors but are instead in place to define and solidify social relations (DeRenzo, 1997).

Poor speech intelligibility may be an additional result of HNCa treatment, which may further complicate and inhibit an individual's desire or capacity to engage socially (Semple et al., 2004). Not only does an individiual's inhibited ability to communicate with others augment issues of social isolation, it may also lead to feelings of embarrassment, lowered self-esteem, and depression which in turn, may impede adherence to rehabilitation or self-care regimens, as well as tobacco and alcohol cessation programs that are crucial for HNCa survivors (Blood, Luther, & Stemple, 1992; Blood et al., 1994; Howren et al., 2012). The extensive range of social challenges faced by individuals who have undergone treatment for HNCa is particularly concerning since it is well documented that social support is correlated with positive adjustment to the experience of disease (McDonough et al., 1996). In essence, is it concerning that the population of HNCa survivors faces a profoundly disabling disease, while also being at an elevated risk for significant social isolation.

The range of deficits experienced by individuals who have received a diagnosis of HNCa are multidimensional and highly interdependent. Accordingly, HNCa is commonly considered to be the most emotionally traumatic cancer diagnosis as a result of the extensive concomitant

biopsychosocial sequelae (Bornbaum et al., 2012). Thus, despite over 4,300 new diagnoses in Canada each year, the impact of HNCa on those who receive this diagnosis far exceeds the incidence of the disease (Canadian Society of Otolaryngology – Head & Neck Surgery, 2013; Giuliani et al., 2016).

Since the beginning of the twenty-first century, substantial medical advances have been made that have improved the efficacy of HNCa treatments (Giuliani et al., 2016; Stanton, Rowland, & Ganz, 2015; Wells, Semple, & Lane, 2015). The advanced techniques for eliminating the disease may yield a more probable medical cure, however, newly cured individuals may be bestowed with residual trauma that leaves them far from healed. The extensive array of the biopsychosocial treatment sequelae of the advanced treatment modalities illustrates that achieving curative intent is often at the expense of the individual's QoL. In essence, the increasing *quantity* of life provided by the treatment advancements does not necessarily equate to increasing *quality* of life. Furthermore, increased quantity of life does not mean that an individual's struggle to cope with and adapt to the disablement experience of HNCa will cease when the transition is made from cancer patient to cancer survivor. In actuality, a new assortment of challenges arises following the completion of curative treatment for HNCa as "survivors experience changes in the frequency of contact with their healthcare team, manage the lingering side effects of treatment, and resume important social roles and activities—all of which can precipitate feelings of distress" (de Moor et al., 2013, p. 562). The collective multifaceted experience of the cancer survivor that is associated with these new challenges is commonly referred to as survivorship (Miller & Shuman, 2016).

Survivorship

It is estimated that approximately two-thirds of individuals diagnosed with HNCa will survive the disease; a figure that is expected to rise with continued advancements in detection and treatment of HNCa (Giuliani et al., 2016; Semple et al., 2004; Stanton et al., 2015). Hassey Dow (2003) explained that the rising number of cancer survivors is also attributable to "changes in the fundamental understanding of genetics, rapid translation of basic science to practice, modification of dose-limiting toxicities, an increase in screening and early detection activities, enhanced rehabilitation and support interventions, and changes in sociocultural factors" (p. 455). Additionally, due to the more favourable prognosis of human papillomavirus-positive oral and oropharyngeal cancers, a projected 90% of HNCa survivors will experience long-term (e.g., > 5 years) survival (LaMonte, 2016; Marur et al., 2010; Vokes, 2012). As a result, there has been a substantial increase in the number of individuals who are surviving HNCa and living longer after diagnosis and treatment of the disease (Giuliani et al., 2016).

From a biomedical perspective, the notion of survival may be understood as a static state of being cancer free, however, survivorship cannot be reduced to a categorical measure of the efficacy of cancer treatment (Miller & Shuman, 2016). If survivorship is considered through a biopsychosocial lens, it becomes apparent that for individuals who have survived HNCa, survivorship is a more complex notion that encompasses the act and process of living through and beyond the diagnosis and treatment (Brearley et al., 2011; Feuerstein, 2007a; Miller & Shuman, 2016; Mullan, 1985). Accordingly, widely accepted conceptualizations of survivorship posit that an individual is considered a survivor, and, thus, enters the survivorship phase of the cancer continuum at the time of initial diagnosis (Giuliani et al., 2016; Miller & Shuman, 2016). It is suggested that "survival begins at the time of diagnosis since that is the point at which

[individuals] must confront their own mortality and the inevitable change in the course of their life moving forward" (Miller & Shuman, 2016, p. 1).

Beginning at the time of diagnosis and continuing until the end of life, survivorship can be conceptualized as a continuous and fluid state (Brearley et al., 2011; Miller & Shuman, 2016). Miller and Shuman (2016) posited that "survival does not occur in a vacuum," (p. 1) as evidenced by the "medical, psychosocial, interpersonal, financial, and functional consequences of disease and its therapies [that] all contribute to [the] experience of the cancer survivor" (Miller & Shuman, 2016, p. 1). As such, the notion of survivorship encompasses the dynamic process of navigating the challenges that are associated with individuals' adjustment and adaptation to the altered life course that evolves from their experience with HNCa. It is worth noting in light of the variety of survivorship definitions that exist, that this conceptualization of survivorship has been employed for the context of this study in order to portray a holistic representation of individuals' experience with HNCa. Furthermore, this definition of survivorship has been selected to highlight the range of biopsychosocial challenges associated with an individual's experience with HNCa that begin at the time of diagnosis and persist for years after the individual has completed treatment.

An increased risk of compromised physical and psychosocial outcomes commonly accompanies the challenges of adjusting to life after cancer (Molina et al., 2012). Evidence suggests that individuals who have received a diagnosis of cancer have the potential to exhibit positive psychosocial adjustment over time; however, a subset of survivors becomes susceptible to diminished psychosocial and physical health, that may arise from the persistent effects of HNCa and its treatment (Stanton et al., 2015). Residual effects of the diagnosis and treatment of cancer can be categorized into long-term and late effects (Cohen et al., 2015). Long-term effects

are demarcated as medical complications acquired during active treatment that continue after treatment completion (Cohen et al., 2015). Medical problems that arise months or years after treatment completion are categorized as late effects (Cohen et al., 2015). Wolff (2007) explained that while the conceptualization of survivorship has "shifted from a narrow focus on the direct effects of anti-cancer therapy" (p. 7), it is still important for the notion of survivorship to encompasses traditional outcomes of cancer and its treatment such as long-term and late effects.

Due to the functional significance of the anatomical region affected by HNCa and its treatment, individuals who have received treatment face an overwhelming collection of long-term and late effects (Cohen et al., 2015; Murphy et al., 2007; Hutton & Williams, 2001). The development of physical long-term and late effects may be influenced by several variables, including type, duration and dose of treatment, location of primary tumour, the presence of regional or distant disease, and patient demographic factors (Cohen et al., 2015). Common physical long-term and late effects of HNCa and its treatment are presented in Table 2. In addition to myriad physical long-term and late effects, a multitude of psychosocial sequelae have also been reported to affect HNCa survivors (Molina et al., 2012; Coughlin, 2008; Stanton et al., 2015). General psychosocial long-term and late effects are summarized in Table 3. It is worth noting that in many cases, these psychosocial effects of survivorship "are more challenging than the defined course of direct anti-cancer therapy" (Wolff, 2007). Moreover, since the psychosocial aspects of the disease are commonly more arduous to contend with than the physical aspects, unresolved suffering in the psychosocial domain of disablement often results in diminished coping and adjustment (McDonough et al., 1996). Concurrent consideration of the physical and psychosocial domains of disablement is advantageous because it allows healthcare providers to observe the influence of each domain on the individual's attitude, behaviour, and

well-being, as well as their compliance and use of healthcare resources (McDonough et al., 1996).

Furthermore, the physical and psychosocial long-term and late effects faced by post-treatment HNCa survivors have a profound effect on their functioning and perceived QoL (Murphy et al., 2007; Bjordal & Kaasa, 1995). As such, the awareness and management of the multitude of treatment sequelae must continue even after the completion of treatment, thereby indicating that active holistic care must also encompass the survivorship phase of the cancer continuum (Miller & Shuman, 2016; Stanton et al., 2015). In essence, owing to the long-term and late effects of HNCa, there is a substantial need to provide survivors with support and assistance through their process of adjusting to the disabling physical and psychosocial treatment-related challenges associated with survivorship (Bornbaum, 2013).

Unfortunately, due to the physical focus of oncological care provision, patients may be hesitant to disclose psychosocial concerns, contributing to common psychosocial challenges "remaining undisclosed and only becoming apparent when [associated] symptoms [of psychosocial morbidity] are overt and individuals are no longer able to cope" (Bornbaum et al., 2012, p. 2163). However, attending to the psychosocial dimension of an individual's experience with HNCa may serve to decrease the extreme strain placed on the healthcare system by the high-utilizers of care who are predominantly those who are experiencing substantial psychosocial morbidity, such as anxiety, depression, and mood disturbances (Carlson & Bultz, 2004). Moreover, if the psychosocial aspects of disablement are highlighted so that health care providers are tuned in to the psychosocial struggles of individuals with HNCa, those who are struggling to cope, and often represent the highest utilizers of care, may be identified and supported proactively before psychosocial morbidity can firmly manifest. This would ultimately

maximize benefits and savings to the healthcare system (Carlson & Bultz, 2004). For instance, increased attention to individuals' psychosocial disablement experience with HNCa has been linked to improved medical outcomes and increased patient satisfaction in addition to decreased health care costs (Bornbaum et al., 2012).

Despite delivering a medical cure, therapeutic endeavors that neglect individuals' subjective experience of disablement can threaten their ability to be resilient in psychological and social domains of well-being (Frank, 1995). In essence, when subjective domains of disablement are ignored, individuals who have completed treatment often reach the end of the clinical pathway before their psychosocial functioning has returned to a homeostatic level. In other words, the clinical pathway rectified the abnormal cell growth that was the cause of the individual's disablement experience with HNCa but has done nothing to encourage or support a resilient response in the survivor. Based on the above considerations, there is a need to investigate the potential for resilience to ameliorate the impact of the biopsychosocial consequences of HNCa and its treatment, not only in hopes of maximizing survivors' QoL, but also to minimize the strain on the healthcare system.

Table 2

Summary of Potential Long-Term and Late Effects of Head and Neck Cancer and its Treatment by Treatment Type

Treatment Type	Long-Term Effects	Late Effects
Surgery (neck dissection, laryngectomy)	Shoulder function • Shoulder mobility, pain Oral health complications • Xerostomia • Dysphagia • Oral infections Musculoskeletal effects • Trismus • Impaired neck motion, pain • Stricture	• Spinal nerve abnormalities • Lymphedema • Neuropathy • Cervical radiculopathy
Radiation (IMRT, mediastinal RT)	Oropharyngeal • Xerostomia • Dysphagia Neuromuscular • Cervical dystonia • Trismus Musculoskeletal • Shoulder dysfunction Integumentary • Radiation dermatitis Lymphovascular • Lymphedema Oral health complications • Xerostomia • Oral infections	Vision • Premature cataracts Cardiovascular • Carotid obstruction • Baroreceptor failure Oropharyngeal • Xerostomia • Dysphagia • Dysarthria Pulmonary • Pulmonary fibrosis Neuromuscular • Cervical dystonia • Trismus • Brachial plexopathy • Cervical radiculopathy Musculoskeletal • Osteonecrosis Lymphovascular • Lymphedema • Carotid stenosis Sensory complications • Hearing loss • Ocular issues • Dysgeusia or loss of taste
Chemotherapy	Neuromuscular • Sensory/motor neuropathy • Sensory ataxia • Gait dysfunction • Vertigo Other effects • Hot flushes/sweats • Weight gain, abdominal obesity • Fatigue/decrease activity • Anemia • Body hair loss • Dry eyes	Neuromuscular • Cardiac abnormality, cardiomyopathy Other • Osteoporosis, fractures • Metabolic syndrome • Cardiovascular disease – possible increased risk of myocardial infarction • Diabetes; decreased sensitivity to insulin and oral glycemic agents • Increased cholesterol • Increased fat mass and decreased lean muscle mass/muscle wasting • Venous thromboembolism • Vertigo • Cognitive dysfunction

Note. From American Cancer Society Head and Neck Cancer Survivorship Care Guidelines, by E. E. W. Cohen et al., 2015, *A Cancer Journal for Clinicians*, *66*(3), p. 213. Reprinted with permission.

Table 3
General Psychosocial Long-Term and Late Effects

- Depression, depressive symptoms
- Distress – multifactorial unpleasant experience of psychological, social, and/or spiritual nature
- Worry, anxiety
- Fear of recurrence
- Pain-related concerns
- Changes in sexual function and/or desire
- Challenges with body image (secondary to surgery, laryngectomy, radiation)
- Challenges with self-image
- Relationship and other social role difficulties
- Return to work concerns and financial challenges

Note. From American Cancer Society Head and Neck Cancer Survivorship Care Guidelines, by E. E. W. Cohen et al., 2015, *A Cancer Journal for Clinicians, 66*(3), p. 214. Reprinted with permission.

To reflect the myriad short and long-term challenges concomitant with survivorship, three phases have been suggested to demarcate typical groupings of potential long-term and late effects. The three phases of survivorship were proposed by Mullan and include "'acute survival,' the phase that includes diagnosis and treatment; 'extended survival,' the phase that begins at the completion of intensive therapy and includes surveillance; and 'permanent survival,' a phase vaguely defined as the period of cure" (as cited in Miller & Shuman, 2016, p. 1). Although specific challenges and experiences may be representative of a certain survivorship phase, the heterogeneity of survivors renders the three phases fluid and dynamic (Feuerstein, 2007a; Stanton et al., 2015). At the outset of their experience with HNCa, individuals encounter a unique subset of challenges related to the diagnosis and treatment that are reflected in the acute phase of survivorship.

Acute phase of survivorship. At the time of diagnosis and commencement of the acute survival phase, the "emotional stress of simply being characterized as a 'patient with cancer' coupled with the realization that [the individual] may bear substantial functional impairment can be significant – even in the event of cure" (Miller & Shuman, 2016, p. 2). This psychosocial disruption elicited by the diagnosis of cancer is evidenced by a higher representation of symptoms of depression and anxiety in survivorship populations (Cohen et al., 2015; Stanton et al., 2015). Mullan (1985) posited that anxiety secondary to the diagnosis of cancer instigates a

"state of mental ill-being that is sometimes more punishing than the biologic presence of the disease" (p. 271). Nonetheless, the "biologic" and physical symptoms of the head and neck malignancies may be already weighing heavily on the individual at the time of initial diagnosis (Miller & Shuman, 2016). For instance, newly diagnosed individuals may already be suffering from speech deficits, dysphagia, fatigue, and pain (Brearley et al., 2011; Cohen et al., 2015; Gritz et al., 1999).

When individuals receive a diagnosis of HNCa they embark on a journey that often creates chaos in all aspects of their daily functioning (Semple et al., 2004). While the duration of the acute survival phase is generally only a few weeks, the time following the initial diagnosis of HNCa is characterized by an inundation of unfamiliar and potentially frightening encounters concomitant with the diagnosis (Miller & Shuman, 2016). At the time of diagnosis, the individual is forced to quickly assimilate a large amount of information about their disease and the corresponding treatment options (Semple et al., 2004). Individuals in the acute phase:

> confront in rapid succession a number of … issues: treatment options; the immediate interpersonal and financial consequences of therapy, including time away from work and income and myriad others; treatment-associated pain and morbidity; the risks inherent to head and neck surgery, radiotherapy, and/or chemotherapy; acquiring new skills, such as tracheostomy, gastrostomy, and wound care; and potentially even anger or guilt over the factors contributing to their development of the disease. (Miller & Shuman, 2016, p. 2)

When individuals encounter the treatment related challenges of the acute survivorship phase, the aforementioned challenges associated with the diagnosis are compounded by disabling symptoms that are a direct effect not of the cancer, but of the treatment itself. Unfortunately, the completion of treatment does not equate to the completion of challenges faced by HNCa

survivors. When individuals enter the extended phase of survivorship they are confronted with a new subset of challenges.

Extended phase of survivorship. Tasks of reassimilation and reentry characterize the extended survival phase that commences following treatment completion (Miller & Shuman, 2016). An individual who has survived a cancer diagnosis and treatment, may be poorly prepared for the reentry period that categorizes the transition from active cancer patient to cancer survivor (Stanton et al., 2015; Mullan, 1985). Consequently, individuals who have survived HNCa, as well as their significant others and caregivers, may hold "unrealistically lofty expectations for rapid recovery … and [may be] surprised by their feelings as treatment ends" (Stanton et al., 2015, p. 161). Individuals may expect that both their health and daily routines will begin to stabilize now that the rigmarole of active treatment has ended (Brearley et al. 2011). However, this expectation may not be entirely realistic and individuals may now face the challenge of readjusting to a new normal. There exists a somewhat myopically comforting linearity of the events associated with the active treatment of HNCa that is discontinued subsequent to treatment completion. Stanton et al. (2015) explained that:

> the months after treatment typically involve loss of the safety net of active treatment and the accompanying supportive milieu offered by frequent visits to health care providers, resumption or alteration of former roles within and outside the home, a decline in social support, and experience of lingering or emerging physical and psychological effects of diagnosis and treatment. (p. 162)

Following recovery from HNCa and its treatment, continued cancer surveillance, innocuous symptoms that may mimic cancer, or the cancer related illness or death of a public figure or family member, can trigger anxiety and distress surrounding fear of recurrence

(Coughlin, 2008; Rolland, 2005; Stanton et al., 2015). Fear of cancer recurrence has a significant impact on individuals who are in the extended phase of survivorship and, thus, should not be minimized (Doyle, 1994). Fear of cancer recurrence is a multidimensional concept that refers to the uncertainty, concern, and associated dysfunctional behaviour regarding the chance that a cancer survivor may have to confront another diagnosis of cancer **(**Howren et al., 2012**)**. It cannot be reduced or minimized as a "transient affective state manifested upon the conclusion of treatment" (p. 6) because in reality, fear of cancer recurrence can persist for years post-treatment (Howren et al., 2012). The survivor's concern that the malignancy may return after the completion of treatment is of particular interest since it is related to an increased use of health care services, as well as poorer QoL for survivors (Stanton et al., 2015). Moreover, the survivor's persistent fear of recurrence augments the individual's risk of diminished mental health that may be experienced in the form of distress, depression, and anxiety (Cohen et al., 2015; Stanton et al., 2015).

The extended phase of survivorship is commonly associated with substantial psychosocial burden (Stanton et al., 2015). Studies have found that individuals commonly experience an escalation of psychosocial distress after treatment has been completed (Bjordal & Kaasa, 1995; Lim, Shon, Paek, & Daly, 2014; Stanton et al., 2015). Following completion of treatment, psychological anxieties of cancer survivors frequently revolve around the uncertainty of cancer recurrence or progression, disablement, and premature death (Coughlin, 2008; Doyle, 1994). Therefore, an amplified sense of physical vulnerability may lead to somatization and subsequent misuse of limited healthcare resources (Doyle, 1994; Lim et al., 2014). Moreover, Misono et al. (2008) found that the "relative increase in suicide risk among persons with cancer was highest in the first five years after diagnosis with cancer" (p. 4733). Although cancer

survivors are still at a heightened risk of suicide for approximately 15 years following their diagnosis when compared to those who had no history of cancer, the risk of suicide among cancer survivors gradually decreases as they transition into the permanent stage of survivorship (Misono et al., 2008).

Permanent phase of survivorship. Miller and Shuman (2016) reported that the permanent phase of survivorship is conceptualized as commencing at the "point of 'cure'" (p. 2), where, from a strictly biomedical perspective, "cure" is widely considered to be reached when the individual has been disease free for five years. As individuals transition into this later survivorship period, acute somatic morbidities have usually subsided, and the individual has had time to psychologically process and resolve their disablement experience with HNCa (Stanton et al., 2015). Nevertheless, survivors may continue to endure the physical and psychosocial sequelae that were experienced in the extended survival phase continually or periodically (Stanton et al., 2015). Individuals may experience continued challenges with "reacclimation to new family or societal roles, coping with the late-effects of therapy, and potentially dealing with second primary cancers" (Miller & Shuman, 2016, p. 2).

In light of the expansive array of concerns and challenges associated with HNCa and its treatment, the process through which an individual successfully bridges the gap between sickness and wellness is of particular interest. Despite all odds, it is possible for positive adaptation to follow the potentially traumatic and adverse experiences of HNCa (Coughlin, 2008). It follows that the consideration and conceptualization of this process of positive adaptation may delineate how survivors may be better equipped to restore wellness after their disabling experiences with HNCa. Since resilience denotes a dynamic process, characterized by positive adaptation in the context of significant adversity (Deshields, Heildand, Kracen, & Dua, 2016; Gillespie,

Charboyer, & Wallis, 2007; Pieters, 2016; Tian & Hong, 2014) it follows that resilience may be a central variable in understanding how to best prepare HNCa survivors to re-establish overall well-being.

In essence, how a HNCa survivor perceives their experience with the biopsychosocial treatment sequelae may potentially be buffered by resilience. As such, owing to the complexity of the disabling consequences of HNCa, individuals' capacity to respond resiliently is particularly relevant in this unique population. Understanding the process of resilience in the population of HNCa survivors may elucidate how some individuals manage to successfully cope with the many sequelae of HNCa and its treatment. In understanding the process of resilience in HNCa survivors, the lessons learned may in turn be applied to help individuals who are struggling to cope with the disabling impact of surviving HNCa re-establish overall wellness.

Resilience

The term resilience refers to an individual's ability to transcend an adverse experience and restore homeostatic functioning in physical, psychological, and social domains of well-being (Gillespie et al., 2007; Pieters, 2016). Put simply, resilience refers to how individuals respond to challenges in their lives and, ultimately, how they rebound from such challenges. Resilience may define how individuals reestablish a sense of balance in their daily living. In essence, an individual's adjustment in the wake of adverse circumstances such as, the disablement experience associated with HNCa, can be conceptualized as the multidimensional process of resilience. Common defining features of definitions of resilience are outlined in Table 4.

Table 4

Commonalities Among Definitions of Resilience

- The capacity of a dynamic system to adapt successfully to disturbances that threaten its function, viability, or development.
- The ability to avoid deleterious behavioural and physiological changes in response to chronic stress.
- A process to harness resources to sustain well-being.
- The capacity to resume positive functioning following adversity.
- A measure of the degree of vulnerability to shock or disturbance.
- A person's ability to adapt successfully to acute stress, trauma, or more chronic forms of adversity.
- The process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress.

Note. Retrieved from *Supportive Relationships and Active Skill-Building Strengthen the Foundations of Resilience: Working Paper 13*, by National Scientific Council on the Developing Child, 2015, p. 1.

The foundation of resilience is laid during childhood and, as such, consideration of the development of resilience is warranted to better understand the roots of resilience that adult HNCa survivors bring with them in their journey with the disease and its treatment. During childhood, protective experiences and adaptive skills accumulate to counterbalance adversity that the child may encounter (National Scientific Council on the Developing Child, 2015). This process of development can be illustrated through the imagery of a balance scale or seesaw, where positive experiences and developmental variables (e.g., supportive relationships, skill building opportunities) load the positive outcomes end of the scale and negative experiences and developmental variables (e.g., exposure to violence, maltreatment, poverty) are stacked onto the negative outcomes end of the balance scale (National Scientific Council on the Developing Child, 2015). The development of resilience is illustrated through this balance scale imagery when, despite a potentially heavy load of negative experiences and variables, the balance scale still tips in the direction of positive outcomes (National Scientific Council on the Developing Child, 2015).

When the development of resilience is visualized using this balance scale model, the representation is not complete without mention of the scale's fulcrum. The fulcrum is integral in the determination of which direction an individual's balance scale will tend to tip. For example, as is the case with any balance scale, if the fulcrum is positioned closer to one end, it is more difficult for the scale to tip in that direction (National Scientific Council on the Developing

Child, 2015). During infancy, the fulcrum is initially positioned based on idiosyncratic predispositions that reflect underlying genetic variances (National Scientific Council on the Developing Child, 2015). As the child encounters positive and negative developmental experiences, the position of the fulcrum may be shifted towards the positive or negative outcome ends by means of positive or negative experiences, respectively (National Scientific Council on the Developing Child, 2015). Resilience is evident when developmental variables and experiences position the fulcrum of the scale to shift the equilibrium so that it is more inclined to tip in the direction of positive outcomes.

Developmental variables that influence the position of the fulcrum and, thus, the development of resilience may be categorized into environmental experiences and biological factors. Resilience is developed through the dynamic interaction between protective experiences in the child's social environment and highly responsive biological systems (National Scientific Council on the Developing Child, 2015). Within the child's developmental environment, the presence of a secure and supportive relationship with a parent, caregiver, or other adult is the single most common variable that predicts the development of resilience (National Scientific Council on the Developing Child, 2015). A stable relationship contributes to the development of resilience by providing the child with personalized responsiveness, scaffolding, and protection, which enable the child to cultivate the key capacities (e.g., executive functioning skills and the capacity for self-regulation of thought, behaviour, and emotion) required for positive adaptation to adversity (National Scientific Council on the Developing Child, 2015).

The biological foundation of the development of resilience is rooted in the child's genes and developing brain circuitry (National Scientific Council on the Developing Child, 2015). A child's gene sequence, gene expression, and neural mechanisms work in combination with his or

her social environment to ultimately influence the potential for resilience to be developed (National Scientific Council on the Developing Child, 2015). For instance, a child's genes dictate the production of proteins in the brain that are responsible for regulating the child's reaction to stress and, thus, have the potential to ameliorate or exaggerate negative outcomes of stress or adversity (National Scientific Council on the Developing Child, 2015).

Sustained exposure to adversity during childhood can cause long-term changes in the size and number of neural connections and circuity in brain regions that are responsible for skills (e.g., behavioural regulation and management of emotional wellness) that are central to the development of resilience (National Scientific Council on the Developing Child, 2015). Other key skills that contribute to the development of resilience during childhood, such as the ability to initiate and sustain social behaviour and form attachment with others, are also influenced by variation in the activation of brain chemicals like oxytocin and vasopressin (National Scientific Council on the Developing Child, 2015). When the aforementioned environmental and biological developmental variables interact in a way that positions the fulcrum of the proverbial resilience balance scale to shift the equilibrium towards positive outcomes, the development of resilience is evident.

The foundation of resilience that is laid in childhood has a lasting impact on how adults respond to adversity, for instance, the experience of HNCa and its treatment. Although factors that promote the development of resilience may be in place in an individual's childhood, resilience is situation-specific; it is not a general trait that is guaranteed in all contexts (National Scientific Council on the Developing Child, 2015). While data that identify and describe resilience in populations of HNCa survivors are currently limited, it is undisputed that the disablement experience associated with HNCa and its treatment is a significant adverse

experience for survivors. Since resilience is conceptualized as a dynamic process of positive adaptation in the context of significant adversity, it is justifiable to conceptualize the adverse experience of HNCa as a viable antecedent for resilience.

Thus, since an individual's experience with HNCa presents as an event of significant adversity that crosses physical, psychological, and social domains of functioning (Bornbaum et al., 2013; Doyle, 1994) it may, elicit a resilient response from a survivor (Pieters, 2016). Enduring adverse circumstances such as those associated with HNCa, that are perceived by the individual to be traumatic, may operate as an antecedent to the expression of a resilient response, which in turn, acts to fundamentally influence an individual's adaptation to the adverse circumstances (Gillespie et al., 2007; Markovitz, Schooten, Arntz, & Peters, 2015). That is, the expression of resilience generally follows a precipitating experience that is perceived by an individual to be traumatic and threatening to his or her overall well-being. Accordingly, resilience is not an arbitrary or indiscriminate reaction, but rather, a response elicited by an experience of significant adversity. For instance, the adverse experience of HNCa may represent a prerequisite condition for the expression of a resilient response from the cancer survivor. In turn, the triggered resilient response positions the cancer survivor to respond in a manner that is more conducive to positive adaptation and, thus, restoration of homeostatic physical, psychological, and social functioning despite the disabling sequelae of HNCa and its treatment.

A holistic conceptualization of resilience acknowledges that an individual's resilient response continues to be shaped by contextual and environmental factors throughout one's life span (Gillespie et al., 2007; Tusaie & Dyer, 2004). Tusaie and Dyer (2004) stated that "although each individual possesses the potential for resilience, an interplay between the individual and broader environment is responsible for the level of resilience" (p. 3). Interactions between the

individual and his or her environment are mediated by a resilient response that can enable the transformation of adverse environmental conditions, into more auspicious conditions (Lim et al., 2014). In essence, a resilient response reflects an interplay between risk factors and protective factors at intrapersonal and environmental levels (Gillespie et al., 2007, Tusaie & Dyer, 2004). Risk factors, or stressors, are characterized by adverse environmental circumstances and detrimental intrapersonal predispositions that may threaten to exert a negative influence on physical, psychological, and/or social functioning. In accordance with the conceptualization of a risk factor, it is apparent that an individual's disablement experience with HNCa represents a significant risk factor. More specifically, distinct stressors within an individual's disablement experience with HNCa may include the occurrence of concerning symptoms, the diagnostic work up, and the receipt of the initial diagnosis (Deshields et al., 2016).

A risk factor may also present in the form of compounded chronic strain from multiple stressors (Tusaie & Dyer, 2004). The chronicity of the stressors associated with HNCa is apparent upon consideration of the extensive physical and psychosocial long-term and late effects of treatment (Deshields et al., 2016; Cohen et al., 2015; Llewellyn et al., 2013). For example, survivors of HNCa commonly encounter considerable challenges to normal functioning that may include voice and speech deficits, dysphagia, difficulty eating, pain, fatigue, distress, depression, anxiety, social isolation, role disruption, visible disfigurement, as well as detriments to body image, self-perception, and emotional expression (Bornbaum et al., 2012; Cohen et al., 2015; Desheilds et al., 2016; Gritz et al., 1999; Miller & Shuman, 2016; Murphy et al., 2007). As such, an individual's experience with HNCa encompasses multiple distinct risk factors that ultimately unite to generate a significant event of adversity that will require the balancing action of protective factors to re-establish the individual's sense of well-being.

Protective factors can be conceptualized as "moderators of risk and adversity that enhance good … outcomes" (Werner, 2000, p. 116). Protective factors ameliorate an individual's response to adverse or stressful circumstances to promote more successful adaptation (Werner, 2000). Protective processes involved in the interplay of a resilient response act at an intrapersonal or environmental level to mitigate the potential threats to an individual's functioning and well-being that may emerge in the context of adverse circumstances. Environmental level protective factors include the presence of social support, while at the intrapersonal level, protective factors include "adaptive coping strategies, optimism, positive emotion, self-coherence, and spirituality" (Min et al., 2013, p. 2470).

Protective factors associated with resilience also encompass competencies involved in the identification or development of resources and strengths in order to navigate stressors and achieve positive adaptation (Wu et al., 2015). These resources and strengths may be external agents, in the form of strong social connectedness, "community resources, infrastructure, or social and cultural factors" (Coughlin, 2008, p. 63), or internal states, in the form of active coping, cognitive reframing, hopefulness, hardiness, self-efficacy, and cognitive flexibility (Coughlin, 2008; Deshields et al., 2016; Gillespie et al., 2007, Lim et al., 2014; Markovitz et al., 2015; Min et al., 2013; Molina et al., 2012).

Garmezy, Masten, and Tellegen (1984) suggested three models that describe the mechanisms through which the aforementioned protective factors can operate: the compensatory model, the challenge model, and the immunity model. In the compensatory model, intrapersonal protective factors and sources of support can counter severe stress or risk factors and, as a result, risk factors and protective factors combine additively to determine how the individual will fare in the context of adversity (Garmezy et al., 1984). Garmezy et al. (1984) explained that in the

challenge model, the presence of risk factors and stress enhances an individual's competence, with the provision that the level of stress caused by the risk factors is not excessive. As such, in the challenge model, a curvilinear relationship characterizes the relation between stress and competence (Garmezy et al., 1984). In the third mechanism proposed by Garmezy et al. (1984), the immunity model, a conditional relationship exists between risk factors and protective factors. In other words, the protective factors temper the negative effect of the risk factors on the individual's capacity for successful adaptation, however, in the absence of risk factors, the protective factors appear to have no perceptible effect (Garmezy et al., 1984). It is worth noting that the three models are not mutually exclusive, for example, in the pursuit of positive adaptation the compensatory, challenge, and immunity models may "operate simultaneously or successively in the adaptive repertoire of a resilient individual" (Werner, 2000, p. 116).

Regardless of the mechanism through which a positive factor may operate, the overall process of resilience can be conceptualized as a trajectory for healthy adaptation and a mechanism that protects against psychosocial distress. Despite this, highly resilient individuals are not immune to negative emotions or maladjustment (Markovitz et al., 2015; Molina et al., 2012). In other words, Rutter explained that "resilience is conceived as an end product of buffering processes that do not eliminate risks and stress but that allow the individual to deal with them effectively" (as cited in Werner, 2000, p. 116). Once again, the value of the bidirectional interplay between risk and protective factors that is characteristic of resilience is apparent; resilient individuals still confront risk factors, however, protective factors operate so that homeostatic functioning may be restored in order to resume overall well-being. In essence, the intrapersonal and environmental protective factors and the competencies of highly resilient individuals may allow them to be better equipped to manage negative emotions regardless of the

precipitating event(s) (Markovitz et al., 2015). It follows that although the confrontation of some degree of adversity and the associated risk factors are to be expected in life, positive adaptation in the context of adverse circumstances may be promoted when protective factors are in place to stimulate the restoration of homeostatic functioning.

If an individual is struggling to restore homeostatic functioning, it is worth noting that the aforementioned protective factors and the mechanisms through which they operate are amenable to cultivation and nurturance at any point in time during the lifespan (Deshields et al., 2016; Gillespie et al., 2007; Pieters, 2016). Therefore, resilience can be viewed as a malleable and cultivable defense mechanism that enables individuals to adapt positively amid potentially adverse disablement experiences (Tian & Hong, 2014). It follows that supporting resilience in HNCa survivors may be a valuable target for adjuvant psychosocial therapies and prophylaxis (Tian & Hong, 2014). Resilience may explain why some survivors overcome the overwhelming challenges associated with HNCa, while others fall victim to the disabling consequences of the disease and its treatment. In essence, it is believed that resilience has the potential to play a positive role in an individual's experience with cancer by buffering cancer-related adverse effects (Wu et al., 2015). Since it is well documented that the adverse effects of HNCa have a detrimental impact on QoL (Doyle, 2005), it follows that the enhancement of resilience may also present an opportunity to improve the quality of life of individuals who have been diagnosed and treated for cancer (Tian & Hong, 2014; Wu et al., 2015). Nevertheless, establishing resilience enhancing practices in oncological care for HNCa survivors is unlikely unless there are data that identify and describe the presence of resilience in this population of survivors.

Given the increasing survival rates and growing HNCa survivorship population, survival can no longer be the primary outcome measure of oncological treatment efficacy (Lawford &

Eiser, 2001). The resultant shift in the perception of HNCa as a chronic illness instead of a life-threatening disease (Farrell & Hassey Dow, 1997), necessitates that QoL is categorically distinct from the rate of biomedically defined survival. In essence, increasing survival rates may equate to increasing *quantity* of life, but by no means do they equate to increasing *quality* of life.

Quality of Life

The global construct of QoL reflects an individual's overall perception of well-being (Murphy et al., 2007). By definition, QoL is a multidimensional construct that includes the three core domains of physical, psychological, and social functioning (Gritz et al., 1999; Murphy et al., 2007). QoL is a highly-individualized construct that is fluid and changes in different contexts and over the course of one's life (Semple et al., 2004). The World Health Organization (WHO) (1997) provides the most widely cited definition, defining QoL as:

> individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment. (p. 1)

Beyond the factors mentioned in the WHO's definition of QoL, individuals' perceived QoL is also affected by their idiosyncratic perspective on dimensions that could include spirituality, sexuality, and intimacy (Gritz et al., 1999). QoL is further influenced by individuals' intrinsic characteristics including their beliefs, values, and past experiences (Murphy et al., 2007). The importance of individuals' subjective perceptions, as well as the influence of objective contextual aspects of the given set of circumstances is recognized in the WHO's definition of QoL (Semple et al., 2004). As such, the objective circumstances surrounding an

individual's disablement experience with HNCa in combination with the intrinsic attributes and subjective perceptions of the individual are likely to idiosyncratically modify QoL.

Accordingly, among the many variables that may influence one's QoL, health related issues and the experience of disease are central (Murphy et al., 2007). Doyle (2005) posited that to "say that the potential effect of a diagnosis of head and neck cancer and the subsequent treatment of such disease is anything but devastating to one's QOL is not unreasonable" (p. 5). Thus, the consideration and assessment of QoL in individuals with HNCa is of notable relevance since the disablement experience of HNCa is associated with numerous health related issues that impact domains of functioning, which in turn, profoundly effects one's QoL (Gritz et al., 1999). For instance, factors such as "physical, social, cognitive, spiritual, emotional, and role functioning as well as psychological symptoms and symptoms such as pain, nausea, and vomiting and fatigue" (Carlson & Bultz, 2004, p. 838) are central issues of the individual's disablement experience with HNCa and are also well documented to impact the individual's valuation of QoL. More specifically, the experience of HNCa has a severely disabling effect on each of the three core domains of QoL: dysphagia, xerostomia, and pain contribute to dysfunction in the physical domain; distress, depression, and visible disfigurement result in dysfunction in the psychological domain; and detriments to eating, communication, and speech functions lead to dysfunction in the social domain. Thus, considering the "potential for morbidity associated with treatment, assessment of quality of life is particularly important with head and neck cancer patients" (Gritz et al., 1999, p. 352).

Furthermore, since the potential for detriments to HNCa survivors' perceived QoL is profound, the assessment of QoL is critical in terms of ensuring optimal provision of care to address the potential consequences of the disease and its treatment that commonly impact QoL.

Murphy et al. (2007) suggested attentiveness to patients' QoL can "(1) facilitate communication between a physician and their patient, (2) identify problems that have significant impact on QoL, (3) guide the physician to screen for problems that impact on QoL, and (4) help physicians prioritize the treatment of problems that develop during treatment" (p. 254). Moreover, QoL measurement instruments allow patients and health care providers to garner a greater understanding of the influence of the HNCa disablement experience on physical, psychological, and social functioning in addition to aiding in decisions related to the modality of treatment that best fulfills individuals' biopsychosocial needs (Howren et al., 2012).

Despite numerous studies that explore the QoL of individuals who have been diagnosed and treated for HNCa, limited data exist on the nature and presence of resilience in this unique cohort of cancer patients. Furthermore, the potential moderating effect of resilience on the QoL of individuals who have completed treatment for HNCa is relatively unknown. If the occurrence of resilience is conceptualized and described within the HNCa survivorship population, the potential role of resilience in maximizing QoL, while minimizing the impact of HNCa, may be investigated (Lawford & Eiser, 2001).

Statement of Problem

The upsurge of medical advancements in oncological care has initiated the growth of the HNCa survivorship population. However, despite delivering a biological cure, advanced medical treatment often leaves individuals who reach the end of the clinical pathway, far from healthy. The increasing number of HNCa survivors ultimately equates to an increasing number of individuals who must face potentially overwhelming biopsychosocial challenges unique to surviving the disease. Thus, it is of increasing concern that the multitude of challenges

commonly faced by HNCa survivors frequently remain on the periphery of the focus of oncological care delivery (Feuerstein, 2007b).

Equally concerning is the fact that the provision of oncological care commonly takes a reactive stance to individuals' functional deficits as opposed to working proactively to support individuals' journeys through the potential challenges associated with HNCa. In effect, individuals must be in a functional deficit before they receive attention from the healthcare system. There is no controversy surrounding the profoundly adverse influence that HNCa and its treatment has on multiple levels of functioning; yet, functional impairments must be overtly manifested before individuals with HNCa receive remedial care. In essence, morbidity at the level of physical, psychological, and social functioning must be firmly manifested before the individual receives suitable attention from the healthcare system. In spite of the inherently reactive stance of oncological care delivery, it may be in the best interest of HNCa survivors if oncological research and care provision adopts a proactive stance that supports survivors before biopsychosocial dysfunction takes hold. A proactive stance could help individuals to positively adapt to their disablement experiences with HNCa before negative adaptation can manifest overtly as psychosocial morbidity that further adds to their disablement.

When oncological care delivers a physical cure for HNCa it is not an indication that the individuals who have completed the curative treatment are psychologically fit (Bjordal & Kaasa, 1995). For example, psychosocial distress, anxiety, and depression commonly become more prominent after regular cancer surveillance ends (Lim et al., 2014; Stanton et al., 2015). Accordingly, the disablement experience of HNCa has a lasting impact on individuals' physical, psychological, and social functioning that persists following the completion of treatment. Since physical, psychological, and social functioning represent the three core domains of individuals'

perceptions of their QoL, trajectories of recovery often show that HNCa survivors' QoL is at its lowest in the period following treatment completion (Howren et al., 2012). When survivors reach the end of the HNCa clinical pathway they will have overcome the objective physical markers of HNCa. Unfortunately, the clinical pathway that delivered these survivors a biological cure has also left them with profound psychosocial dysfunction. The transition into extended survivorship represents a stage of the cancer continuum in which individuals are most vulnerable to psychosocial morbidities and are simultaneously receiving minimal care since the supportive milieu of active treatment has come to an end.

Although a subset of survivors become susceptible to diminished psychosocial health and QoL that may arise from the extensive sequelae of HNCa and its treatment, evidence suggests that individuals have the potential to reestablish homeostatic functioning. The recovery trajectories for HNCa survivors display obvious individual differences that show that some individuals reestablish homeostatic functioning following treatment completion, while others continue to experience substantial dysfunction secondary to HNCa and its treatment (Howren et al., 2012). Accordingly, the question of why some individuals experience extreme impairment while others have the ability to restore homeostatic levels of functioning in the context of comparable adverse circumstances is central to the understanding of the survivorship phase of the HNCa disablement experience (Carver, 1998). A potential answer rests on the notion that resilience may counter the cumulative impact of the HNCa experience, and act as a "protective factor against [the development of] psychopathological symptoms" through the period of survivorship (Markovitz et al., 2015, p. 1644). Tremendous potential may exist for the minimization of the psychosocial challenges associated with HNCa and its treatment, if individuals with a potentially higher vulnerability of developing psychosocial morbidity are

screened and identified before such morbidity can manifest. Markovitz et al. (2015) suggested that lower levels of resilience may be indicative of higher potential vulnerability to psychosocial morbidity. Thus, screening for resilience presents as an opportunity for taking a proactive stance in an attempt to minimize the profound impact of HNCa before it can manifest as psychosocial morbidity in survivors.

Markovitz et al. (2015) posited that "screening for resilience can lead to early detection and selection of patients with lower resilience and potentially higher vulnerability to develop emotional problems" (p. 1644). As such, screening for resilience may present as an initial step in a proactive approach to support positive adaptation within the context of individuals' disablement experiences with HNCa. Supporting resilience in those who have been screened and identified to be less resilient may provide individuals with a fighting chance of reestablishing homeostatic levels of functioning in psychological and social domains when they reach the end of the clinical pathway. Research must be conducted to assess the utility of taking a proactive stance to the psychosocial care of HNCa survivors. Unfortunately, the majority of psychosocial cancer research has concentrated on the diagnosis and treatment phases of the cancer continuum, with little focus paid to the extended survivorship period (Stanton et al., 2015). Furthermore, screening for resilience will not become an established practice in oncological care unless there are data to substantiate the occurrence of resilience in the HNCa survivorship population. While data on resilience exist for other oncological populations, to date, little empirical research has sought to describe the occurrence of resilience within the unique population of individuals who have completed treatment for HNCa.

Consequently, this research study sought to investigate how resilience may influence individuals' QoL in the context of their experience of surviving HNCa. The primary aim of the

present study centred on the identification of the presence of resilience within the HNCa survivorship population. This study also aimed to explore the potential for resilience to mitigate, at least to some extent, the psychosocial sequelae of HNCa, and, thus, the consequential detriments to QoL. Through an increased understanding of resilience within the HNCa survivorship population, the role of resilience in minimizing the impact of the disease, while maximizing survivors' QoL may be assessed. As such, the specific objectives of the study were as follows:

1. Identify the presence of resilience in a sample of individuals who have completed curative treatment for HNCa.
2. Determine if a relationship exists between individuals' resilience and overall QoL in the context of their survivorship experience with HNCa.

CHAPTER 2

Method

Participants

Individuals who had completed treatment for HNCa served as the primary population of interest for this study. Participants were recruited during their transition into the extended phase of survivorship that is indicative of the time period following treatment completion. Male and female survivors who were between 25 and 85 years of age were eligible to participate in this study. The Department of Otolaryngology - Head and Neck Surgery Clinic at London Health Sciences Centre, Victoria Campus, London, Ontario, Canada served as the primary location for participant recruitment.

Demographic information. A total of 39 individuals were initially identified as potential participants. Of the initially identified individuals, 32 consented to participate. Completed study packages were received from 31 of the consented individuals, equating to a return rate of 97%. Of the 31 completed study packages, eight were returned by female participants (25.8%) and 23 by male participants (74.2%). The mean age of the consenting participants was 62.7 years (range = 39.7 to 82.8 years), with a mean age of 57.6 for the female participants (range = 39.7 to 74.6) and 64.5 for the male participants (range = 42.5 to 82.8 years). Complete participant demographic information is presented in Table 5.

Table 5
Demographic Information of Study Participants

Demographic Variable	n	%
Sex		
Male	23	74.2
Female	8	25.8
Mean Age	62.72	N.A.
Marital Status		
Married	19	61.4
Separated	1	3.2
Divorced	1	3.2
Common-law	5	16.1
Engaged	1	3.2
Single	3	9.7
Dating	1	3.2
Highest Level of Education Achieved		
Did not complete High School	5	16.1
Completed High School	14	45.2
Completed College	7	22.6
Undergraduate University Degree	2	6.4
Post-graduate University Degree	3	9.7
Occupational Status		
Currently Working – Full-time	8	25.8
Currently Working – Part-time	3	9.7
Volunteer	1	3.2
Retired	16	51.7
Unemployed	1	3.2
Disability Leave	1	3.2
Volunteered and Retired	1	3.2
Household Income		
< $25,000	3	9.7
$25,000 - $40,000	2	6.4
$40,001 - $55,000	4	12.9
$55,001 - $70,000	4	12.9
$70,001 - $85,000	3	9.7
> $85,000	7	22.6
Undisclosed	8	25.8

Site and clinical stage of cancer and method of treatment. The participants had completed varied treatment modalities for malignancies in various primary sites within the head and neck region. The predominant diagnosis among participants was oral cavity cancer (n = 19),

followed by laryngeal cancer (n = 8). The majority of the participants' tumours were clinically staged as T_1N_0 (n=11). Of the 31 participants, 14 received surgery as the sole treatment modality, nine received surgery and radiation therapy, and five received surgery, radiation therapy, and chemotherapy. Table 6 presents a summary of the primary sites of cancer origin, the clinical stage of the tumours and the distribution of treatment modalities employed in the management of the participants' HNCa. The length of time elapsed since the participants' diagnosis of HNCa ranged from seven to 58 months (mean = 25.7). The time elapsed since treatment completion ranged from one to 59 months (mean = 21.9). The distribution of the time since diagnosis and treatment completion among the participants are presented in Table 7.

Table 6
Site and Clinical Stage of Cancer and Modality of Treatment

Variable	n	%
Site of Cancer		
Oral Cavity	19	61.4
Larynx	8	25.8
Nasopharynx	1	3.2
Lymph Nodes	1	3.2
Larynx and Thyroid	1	3.2
Oral Cavity and Thyroid	1	3.2
Clinical Stage of Cancer		
Carcinoma in situ	2	6.4
T_1N_0	11	35.7
T_1N_1	1	3.2
T_2N_0	2	6.4
T_2N_1	1	3.2
T_2N_2	3	9.7
T_3N_0	3	9.7
T_3N_2	2	6.4
T_4N_0	3	9.7
T_4N_1	2	6.4
T_XN_2	1	3.2
Modality of Treatment		
Surgery	14	45.2
Radiation Therapy	2	6.4
Chemoradiation Therapy	1	3.2
Surgery and Radiation Therapy	9	29.1
Surgery, Radiation Therapy, and Chemotherapy	5	16.1

Table 7
Time Since Diagnosis and Treatment Completion

Variable	n	%
Time Since Diagnosis		
<10 months	5	16.1
10-19 months	8	25.8
20-29 months	6	19.3
30-39 months	7	22.7
40-49 months	1	3.2
50> months	4	12.9
Time Since Treatment Completion		
<10 months	8	25.8
10-19 months	7	22.7
20-29 months	8	25.8
30-39 months	4	12.9
40-49 months	2	6.4
50> months	2	6.4

Inclusion criteria. The diagnosis of HNCa, as well as the completion of treatment was required for participant inclusion in this investigation. Accordingly, to participate, individuals were required to be in the extended phase of survivorship, defined by tasks of reassimilation and reentry following treatment completion (Miller & Shuman, 2016). Participation was limited to individuals that were a minimum of one month, but no more than five years beyond the end of curative treatment, irrespective of treatment modality. Self-reported good general health exclusive of their diagnosis of HNCa was required. Inclusion criteria further stipulated a minimum age of 25 years and maximum age of 85 years for participation. All participants were required to display adequate English proficiency at the time of recruitment and formal consent.

Exclusion criteria. Individuals were excluded from participation in this study if they had received a previous diagnosis of non-HNCa regardless of its location. If an individual had experienced a recurrence of HNCa they were also excluded. Individuals that had been diagnosed and treated for skin cancer (basal cell, squamous cell, or melanoma) in the head and neck region

were not permitted to participate. Exclusion from participation was also a result of treatment that was ongoing. If completion of curative treatment occurred less than one month or more than five years prior to participation, it excluded individuals from being recruited. If the individual was younger than 25 years of age, or older than 85 years of age, participation was prohibited. Finally, individuals were excluded from participation if their English proficiency was too low to provide informed consent and complete research tasks required for study involvement.

Procedure

Data collection. This research study was a cross-sectional, self-report, survey design. In accordance with the aforementioned inclusion and exclusion criteria, patients' charts were reviewed to assess participation eligibility. First contact with eligible potential participants was made through their otolaryngologist/surgeon during routine follow-up visits that occurred after the completion of treatment. At that time, the individual was informed of the general purpose of the study by their otolaryngologist. The potential participant only made contact with the primary researcher if continued interest in participation was indicated by the individual. As such, the primary population of interest may be considered a sample of convenience, since their accessibility to the researcher was granted by the partnership with the Department of Otolaryngology – Head and Neck Surgery Clinic. Consecutive sampling was used to recruit the participants.

Upon introduction to the researcher, comprehensive details of study participation were conveyed through a written letter of information, in conjunction with a verbal explanation. Individuals who indicated sustained interest in study involvement then received the package of study materials. At this point, all participants gave informed consent in compliance with ethical approval granted by the Western University Health Sciences Ethics Board (REB Approval #

108785). Upon completion of informed consent, a coded participant number known only to the investigators was assigned to each participant. The participant codes ensured that data gathered from participants were free of any personal identifiers that may have linked individuals to their respective data.

Enclosed in the package of study materials was: the formal letter of information and consent, a demographic information inquiry form, one validated, self-report questionnaire pertaining to the collection of resiliency data, two validated, self-report questionnaires pertaining to QoL data collection, and a contact list for local psychological support services and organizations that offer support to individuals that have experienced the disablement associated with HNCa. The package of study materials was either filled out on the spot, or in some instances, taken away and returned by mail at a later date. A prepaid and pre-addressed envelope for the return of the package of study materials was provided if the participant elected to complete the package of study materials off site. The aforementioned stipulations served as the grounds for formal ethical approval, which was granted by the Western University Health Sciences Ethics Board before study commencement (REB #108785); copies of the initial approval and amendment approval for this study are provided in Appendices A and B, respectively.

Measurement instruments. This study collected data to identify the presence of resilience and its potential protective role in buffering the adverse effect of HNCa on QoL by employing three validated, self-report measurement instruments. To gather data pertaining to resilience, the Connor-Davidson Resilience Scale (CD-RISC) was utilized. The European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), supplemented by The European Organisation for Research and Treatment of Cancer

Head and Neck Cancer Module (EORTC QLQ-H&N35) were administered to gather the QoL data.

The Connor-Davidson Resilience Scale (CD-RISC). The Connor-Davidson Resilience Scale is a 25-item self-report measure of resilience. This measurement instrument distinguishes between individuals with higher and lower levels of resilience (Ahern, Kiehl, Sole, & Byers, 2006). Each item is rated on a 5-point Likert scale, ranging from zero to four. For each item, participants indicate the degree to which the item prompt is true within the context of their life. For example, the prompt for item one states "I am able to adapt when changes occur," and the participant responds by indicating that this prompt is "not true at all" with a score of zero, "rarely true" with a score of one, "sometimes true" with a score of two, "often true" with a score of three, and "true nearly all the time" with a score of four. The CD-RISC is scored by a simple summation of the responses for the 25 items (Davidson & Connor, 2016). As such, zero is the minimum score and 100 is the maximum score, where higher scores reflect higher levels of resilience (Davidson & Connor, 2016). A clinically significant score or threshold has not yet been established and, thus, interpretation of the CD-RISC total score remains a subjective evaluation of the summation of the participants responses to the 25-items. The CD-RISC "demonstrates sound psychometric properties, with good internal consistency and test-retest reliability, [and] exhibits validity relative to other measures of stress and hardiness" (Connor & Davidson, 2003, p. 81).

The CD-RISC was developed for use within a wide selection of populations including primary care outpatients (Tusaie & Dyer, 2004); however, this measure has not been explicitly developed for application within HNCa survivors. Despite this, Connor and Davidson (2003) suggest that the scale can be used in the investigation of positive adaptation in the context of

adverse circumstances, and as a tool for screening individuals who may be at higher risk of negative adaptation. As discussed previously, a survivor's disablement experience with HNCa is commonly characterized by a succession of traumatic events that are justifiably representative of adverse circumstances (Molina et al., 2012). For example, individuals who have faced the disablement experience of HNCa are subjected to a progression of adverse events that begin at the onset of concerning symptoms and the initial receipt of diagnosis, and continue even after treatment completion in the form of profound detriments to numerous domains of functioning that may involve speech deficits, dysphagia, pain, fatigue, depression, visible disfigurement, and social isolation. As such, individuals that have received treatment for HNCa may be at a heightened risk of negative adaptation in the domains of psychological, social, and physical functioning (Doyle, 1994). Accordingly, application of the CD-RISC to the population of HNCa survivors holds justifiable utility.

The European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Study Group developed the EORTC QLQ-C30 as a cancer specific QoL measurement instrument. The QLQ-C30 is a 30-item questionnaire that is simple and brief to complete, thereby enhancing its use as a self-report measurement instrument (Aaronson et al., 1993). The items in this core questionnaire cover concerns relevant to cancer patients irrespective of the site of disease (Bjordal et al., 1994) and are representative of the multidimensionality of the construct of QoL (Aaronson et al., 1993). The 30 items are categorized into five Functioning Scales (Physical, Role, Cognitive, Emotional, and Social), three Symptom Scales (Fatigue, Pain, and Emesis), six Single Item Measures (Dyspnea,

Insomnia, Appetite Loss, Constipation, Diarrhea, and Financial Difficulties), and a Global Health Status/QoL Scale (Aaronson et al., 1993; Bjordal et al., 1994).

The first 28 items are related to the participant's perceived functioning and experience of various symptoms relevant to their experience with cancer. Participants indicate their responses to these items on a four-point Likert scale coded with four response categories: "not at all" (1), "a little" (2), "quite a bit" (3), and "very much" (4) (Aaronson et al., 1993). QLQ-C30 items 29 and 30 seek information regarding participants' perceptions of their global health and overall QoL, respectively, and are rated on Likert scales that range from one to seven, where a response of one indicates "very poor" overall health or QoL and a response of seven indicates "excellent" overall health or QoL. Raw scores for each scale are generated through a calculation of the average of the items that contribute to the scale (Fayers et al., 2001). The raw scores for each of the 14 scales are then standardized through linear transformation so each scale score has the same range of 0 to 100 (Fayers et al., 2001). Following linear transformation, a high score on a scale of functioning is indicative of a high or healthy ("better") level of functioning (Aaronson et al., 1993). Similarly, a transformed scale score on the Global Health Status/QoL Scale suggests a high health status or QoL (Aaronson et al., 1993). Conversely, a high score for a symptom scale or single item measure indicates a high level of symptomology or challenge ("worse" level of symptoms) (Aaronson et al., 1993). As such, the transformed scores for the various scales require careful interpretation. The QLQ-C30 has been validated in diverse cancer populations and has been shown to have strong psychometric properties (Sherman et al., 2000).

The European Organisation for Research and Treatment of Cancer Head and Neck Cancer Module (EORTC QLQ-H&N35). The EORTC QLQ-H&N35 is a "head and neck cancer specific questionnaire module designed to be used in quality of life assessments before, during,

and after radiotherapy and surgery, with or without combinations with chemotherapy" (Bjordal et al., 1994, p. 879). It is a 35-item self-report measurement instrument intended to be used as a supplement to the core QLQ-C30 questionnaire. The items of the QLQ-H&N35 concern issues associated with the disease and treatment related symptoms and side effects, social function, and sexuality that are concomitant with the HNCa disablement experience. The items are separated into seven multi-item scales that address pain, swallowing, problems with senses, problems with speech, trouble with social eating, trouble with social contact, and issues pertaining to sexuality (Aaronson et al., 1993). The QLQ-H&N35 also contains 11 single items that pertain to issues with teeth, opening the mouth, dry mouth, sticky saliva, coughing, feeling ill, use of pain killers, use of nutritional supplements, use of a feeding tube, weight loss, and weight gain (Aaronson et al., 1993).

Participants respond to the first 30 items using the same four-point scale that is utilized in the QLQ-C30. The final five items are scored on a two-point scale coded with two response categories: "yes" (1) and "no" (2) (Aaronson et al., 1993). The raw scores are then transformed using the same method of linear transformation used in the QLQ-C30 core questionnaire (Fayers et al., 2001). Once transformed, higher scores for all scales and single items indicate a higher perceived level of challenge or problems in the scale's content area (Aaronson et al., 1993). Strong psychometric properties have been established for this measurement instrument (Bjordal et al., 1994). This EORTC site specific module was completed concurrently with the core questionnaire in this study to garner a more thorough valuation of participants' perceived QoL and to offer supplementary data pertinent to assessing QoL in individuals with HNCa (Aaronson et al., 1993).

Data analysis. Upon receipt of completed packages of study materials, the standard scoring procedures for each measurement instrument were used to calculate participants' scores for each of the three utilized questionnaires. While the CD-RISC is scored through simple summation of the responses to the 25 items, the scoring procedures for the QLQ-C30 and QLQ-H&N35 are more complex and are summarized in Appendix H. The resultant scores obtained from the CD-RISC, QLQ-C30, and QLQ-H&N35 were then recorded.

SPSS Statistics Software was used in the statistical analyses of the data. Descriptive statistics were calculated: measures of central tendency were calculated to summarize the typical distribution of the data collected from the CD-RISC, QLQ-C30, and QLQ-H&N35 and measures of dispersion were calculated to describe the variability around the measures of central tendency. Correlational analysis using SPSS Statistics software was used to determine potential statistically significant relationships between the scores gathered from the CD-RISC, QLQ-C30, and QLQ-H&N35. Statistical analysis also included nonparametric Mann-Whitney U-tests to compare potential differences in male and female participants' CD-RISC total scores and Global Health Status/QoL scale scores since the data were not normally distributed. Additionally, observational analyses were completed to garner anecdotal descriptions of trends between applicable demographic variables and scores for resilience and QoL.

CHAPTER 3

Results

In the sections to follow, the results of this study will be presented. To begin, participant response rates were examined and descriptive statistics for the CD-RISC, EORTC QLQ-C30, and EORTC QLQ-H&N35 were calculated. Correlational analysis of the three measurement instruments was completed, as well as observational analysis of variables including sex, age, site of cancer, clinical stage of cancer, treatment modality, time since diagnosis, and time since treatment completion.

Response Rates

Thirty-nine individuals were initially identified as potential participants. Of these, 32 consented to participate. Those who chose not to participate predominantly cited time restraints as the primary reason. All but one of the consented participants completed the package of study materials on site (n=30); one completed the package off site and returned it by mail. Although one other individual agreed to complete the package off site, it was never returned. Thus, overall 97% (n = 31) of the consented participants completed the package of study materials.

Descriptive Statistics

Connor-Davidson Resilience Scale (CD-RISC). The mean, median, and mode, as well as the standard deviation and range were calculated for the raw score of each of the 25 items of the CD-RISC. After total scores were calculated through the standard process of simple summation of the participants' responses to the 25 items, measures of central tendency and dispersion for the total scores were generated. These data are summarized in Table 8. Of the 25 items, the mean was highest for item 25 ("I take pride in my achievements.") and lowest for item

3 (“When there are no clear solutions to my problems, sometimes fate or God can help.”). The highest standard deviation corresponded to item 3, while the lowest standard deviation was found for item 10 (“I give my best effort no matter what the outcome may be.”).

One participant failed to respond to items 7 and 15. When responses are missing from the CD-RISC, the scale is still considered valid when a minimum of 75% of the measure is completed (a minimum of 19 items). As such, the incomplete measure was considered valid and these data were included in analyses. In accordance with the prescribed instructions for the management of missing responses on the CD-RISC, the missing responses were replaced with the rounded mean score for the other items on the scale (mean = 3) for calculations pertaining to total scores. The calculations for measures of central tendency and dispersion for items 7 and 15 were made excluding each respective item’s missing response and, as such, the sample value was adjusted accordingly (N = 30 for item 7 and 15).

Table 8
Measures of Central Tendency and Dispersion for CD-RISC

Item Number	N	Mean	Median	Mode	Range	SD
Q1	31	3.29	4	4 (17)	3	0.94
Q2	31	3.16	4	4 (19)	4	1.37
Q3	31	2.23	2	4 (12)	4	1.69
Q4	31	3.35	4	4 (18)	4	0.95
Q5	31	3.35	4	4 (18)	4	0.95
Q6	31	3.26	4	4 (20)	4	1.26
Q7	30	2.93	3	4 (12)	4	1.23
Q8	31	3.45	4	4 (17)	2	0.68
Q9	31	2.68	3	4 (13)	4	1.42
Q10	31	3.48	4	4 (17)	2	0.63
Q11	31	3.45	4	4 (18)	4	0.85
Q12	31	3.26	3	3/4* (14)	4	0.93
Q13	31	3.23	4	4 (17)	4	1.12
Q14	31	3.13	3	4 (14)	4	1.02
Q15	30	3.17	3.5	4 (15)	4	1.12
Q16	31	3.10	3	4 (15)	4	1.08
Q17	31	3.03	3	4 (13)	4	1.08
Q18	31	3.06	3	4 (15)	4	1.32
Q19	31	3.13	4	4 (16)	4	1.09
Q20	31	3.10	3	3 (13)	3	0.83
Q21	31	3.23	3	4 (15)	4	1.06
Q22	31	3.42	4	4 (19)	4	0.92
Q23	31	2.90	3	4 (13)	4	1.27
Q24	31	3.35	4	4 (16)	4	0.88
Q25	31	3.52	4	4 (20)	4	0.85
Total Score	31	79.26	85	88/96* (3)	90	17.69

*Multiple modes exist, both are presented.
Parenthetical values present the frequencies.

European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). The mean, median, mode, range, and standard deviation were also calculated for each of the 30 questions on the QLQ-C30 (see Table 9), as well as for the five Functioning Scales (Physical, Role, Cognitive, Emotional, and Social), three Symptom Scales (Fatigue, Pain, and Emesis), six Single Item Measures (Dyspnea, Insomnia, Appetite

Loss, Constipation, Diarrhea, and Financial Difficulties), and the Global Health Status/QoL Scale (see Table 10). The values that appear in Table 10 represent the scores for each scale and, thus, values are the result of raw score calculations followed by linear transformation to generate scores that all range from 0 to 100 (see Appendix H for General Principles of Scoring the QLQ-C30). It is worth noting that higher scores for the scales of functioning and Global Health Status/QoL reflect better levels of functioning and QoL, respectively, while higher scores for the Symptom Scales and Single Item Measures indicate greater perceived challenge (Aaronson et al., 1993).

Among the items that contribute to the Functioning Scales, Symptoms Scales, and Single Item Measures (questions 1 to 28), the highest mean score corresponded to question 11 ("Have you had trouble sleeping?"). Question 15 ("Have you vomited?") had the lowest mean score. The standard deviation was found to be greatest for question 11 ("Have you had trouble sleeping?") and the least for question 15 ("Have you vomited?"). Questions 29 and 30 were not included in the analysis of the first 28 questions since they are scored using seven-point Likert scales not the four-point Likert scales used for questions 1 to 28. Among the two questions that contribute to the Global Health Status/QoL Scale, the higher mean score corresponded to question 29 ("How would you rate your overall health during the past week?"). Question 30 ("How would you rate your overall quality of life during the past week?") had a greater standard deviation when compared with item 29.

Among the five Functioning Scales, the Role Functioning Scale was found to have the highest mean, while the Emotional and Social Functioning Scales had lowest means. The greatest standard deviation for the Functional Scales was found for the Social Functioning Scale, while the lowest was found for the Physical Functioning Scale. For the Symptom Scales and

Single Item Measures, the Insomnia Single Item Measure and the Nausea and Vomiting Symptom Scale had the highest and lowest means and standard deviations, respectively.

Table 9

Measures of Central Tendency and Dispersion for Items of EORTC QLQ-C30

Item Number	N	Mean	Median	Mode	Range	SD
Q1	31	1.65	1	1 (16)	2	0.76
Q2	31	1.55	1	1 (18)	2	0.72
Q3	31	1.06	1	1 (29)	1	0.25
Q4	31	1.03	1	1 (30)	1	0.18
Q5	31	1.03	1	1 (30)	1	0.18
Q6	31	1.23	1	1 (26)	2	0.56
Q7	31	1.26	1	1 (25)	2	0.58
Q8	31	1.39	1	1 (21)	3	0.67
Q9	31	1.48	1	1 (20)	2	0.72
Q10	31	1.55	1	1 (18)	3	0.77
Q11	31	1.74	1	1 (16)	3	0.93
Q12	31	1.52	1	1 (17)	3	0.68
Q13	31	1.26	1	1 (23)	1	0.45
Q14	31	1.16	1	1 (26)	1	0.37
Q15	31	1.00	1	1 (31)	0	0.00
Q16	31	1.29	1	1 (25)	3	0.69
Q17	31	1.10	1	1 (28)	1	0.30
Q18	31	1.65	2	1 (15)	3	0.76
Q19	31	1.42	1	1 (21)	2	0.67
Q20	31	1.13	1	1 (27)	1	0.34
Q21	31	1.42	1	1 (20)	3	0.67
Q22	31	1.45	1	1 (21)	3	0.77
Q23	31	1.35	1	1 (23)	3	0.71
Q24	31	1.45	1	1 (22)	3	0.85
Q25	31	1.39	1	1 (20)	2	0.56
Q26	31	1.39	1	1 (23)	3	0.80
Q27	31	1.45	1	1 (21)	3	0.77
Q28	31	1.10	1	1 (29)	2	0.40
Q29	31	5.61	6	7 (11)	5	1.36
Q30	31	5.58	6	7 (12)	5	1.57

Parenthetical values present the frequencies.

Table 10
Measures of Central Tendency and Dispersion for EORTC QLQ-C30 Scale scores

Scale	N	Mean	Median	Mode	Range	SD
Global health status/QoL Scale	31	76.61	83.33	100.00 (9)	83.33	22.92
Functional Scales						
Physical Functioning	31	91.18	93.33	100.00 (15)	33.33	9.95
Role Functioning	31	91.94	100.00	100.00 (23)	50.00	14.83
Emotional Functioning	31	86.02	91.67	100.00 (15)	75.00	19.99
Cognitive Functioning	31	91.40	100.00	100.00 (19)	50.00	12.82
Social Functioning	31	86.02	100.00	100.00 (21)	100.00	24.38
Symptom Scales						
Fatigue	31	18.99	11.11	0.00 (13)	66.67	19.92
Nausea & Vomiting	31	2.69	0.00	0.00 (26)	16.67	6.23
Pain	31	15.05	0.00	0.00 (19)	66.67	22.51
Single Item Measures						
Dyspnea	31	12.90	0.00	0.00 (21)	100.00	22.24
Insomnia	31	24.73	0.00	0.00 (16)	100.00	30.99
Appetite Loss	31	8.60	0.00	0.00 (23)	33.33	14.83
Constipation	31	9.68	0.00	0.00 (25)	100.00	23.08
Diarrhea	31	3.23	0.00	0.00 (28)	33.33	10.02
Financial Difficulties	31	3.23	0.00	0.00 (29)	66.67	13.21

Parenthetical values present the frequencies.

European Organisation for the Research and Treatment of Cancer Head and Neck Cancer Module (EORTC QLQ-H&N35). Table 11 displays the measures of central tendency and dispersion for the 35 items of the QLQ-H&N35. The highest mean was found for question 11 (“Have you had a dry mouth?”), while the lowest mean response was observed for question 33 (“Have you used a feeding tube?”). The greatest standard deviation was found for question 9 (“Have you had problems with your teeth?”), while the least was found for question 33 (“Have you used a feeding tube?”).

The QLQ-H&N35 is scored using the same principles as the QLQ-C30, thus, linear transformation generates scale scores so the seven Symptom Scales and 11 Single Item Measures have the same potential range. For all scales of the QLQ-H&N35, a higher score reflects greater

perceived challenge (Aaronson et al., 1993). Measures of central tendency and dispersion for QLQ-H&N35 scale scores are shown in Table 12. The highest mean corresponded to the Dry Mouth Single Item Measure, while the lowest mean corresponded to the Feeding Tube Single Item Measure. The standard deviation was greatest for the Nutritional Supplements Single Item Measure and lowest for the Swallowing Symptom Scale.

Table 11

Measures of Central Tendency and Dispersion for Items of EORTC QLQ-H&N35

Item Number	N	Mean	Median	Mode	Range	SD
Q1	31	1.48	1	1 (22)	3	0.85
Q2	31	1.32	1	1 (23)	2	0.60
Q3	31	1.52	1	1 (21)	3	0.89
Q4	31	1.23	1	1 (24)	1	0.43
Q5	31	1.19	1	1 (26)	2	0.48
Q6	31	1.16	1	1 (29)	3	0.64
Q7	31	1.58	1	1 (20)	3	0.96
Q8	31	1.19	1	1 (27)	3	0.60
Q9	31	1.84	1	1 (18)	3	1.13
Q10	31	1.42	1	1 (24)	3	0.89
Q11	31	2.32	2	2 (12)	3	1.01
Q12	31	1.94	2	1 (15)	3	1.09
Q13	31	1.32	1	1 (24)	3	0.70
Q14	31	1.61	1	1 (18)	3	0.88
Q15	31	1.81	2	2 (18)	3	0.70
Q16	31	1.55	1	1 (19)	3	0.85
Q17	31	1.26	1	1 (25)	2	0.58
Q18	31	1.26	1	1 (25)	2	0.58
Q19	31	1.52	1	1 (20)	3	0.85
Q20	31	1.42	1	1 (24)	3	0.89
Q21	31	1.55	1	1 (23)	3	1.03
Q22	31	1.55	1	1 (21)	3	0.93
Q23	31	1.55	1	1 (19)	3	0.81
Q24	31	1.48	1	1 (21)	3	0.81
Q25	31	1.29	1	1 (25)	3	0.69
Q26	31	1.35	1	1 (23)	3	0.71
Q27	31	1.26	1	1 (26)	3	0.68
Q28	31	1.23	1	1 (26)	3	0.62
Q29	31	1.65	1	1 (18)	3	0.95
Q30	31	1.61	1	1 (18)	3	0.92
Q31	31	1.32	1	1 (21)	1	0.48
Q32	31	1.35	1	1 (20)	1	0.49
Q33	31	1.03	1	1 (30)	1	0.18
Q34	31	1.23	1	1 (24)	1	0.43
Q35	31	1.26	1	1 (23)	1	0.45

Parenthetical values present the frequencies.

Table 12
Measures of Central Tendency and Dispersion for EORTC QLQ-H&N35 Scale scores

Scale	N	Mean	Median	Mode	Range	SD
Symptom Scales						
Pain Scale	31	12.90	0.00	0.00 (18)	66.67	19.58
Swallowing Scale	31	9.41	0.00	0.00 (18)	58.33	15.92
Senses Scale	31	15.59	16.67	0.00 (14)	66.67	18.73
Speech Scale	31	17.56	11.11	0.00 (13)	77.78	22.37
Social Eating Scale	31	16.94	0.00	0.00 (18)	100.00	26.74
Social Contact Scale	31	9.25	0.00	0.00 (22)	80.00	18.27
Sexuality Scale	31	20.97	0.00	0.00 (16)	100.00	30.11
Single Items						
Teeth	31	27.96	0.00	0.00 (18)	100.00	37.61
Opening Mouth	31	13.98	0.00	0.00 (24)	100.00	29.53
Dry Mouth	31	44.09	33.33	33.33 (12)	100.00	33.76
Sticky Saliva	31	31.18	33.33	0.00 (15)	100.00	36.45
Coughing	31	26.88	33.33	33.33 (18)	100.00	23.44
Felt Ill	31	8.60	0.00	0.00 (25)	66.67	19.18
Pain Killers	31	32.26	0.00	0.00 (21)	100.00	47.52
Nutritional Supplements	31	35.48	0.00	0.00 (20)	100.00	48.64
Feeding Tube	31	3.23	0.00	0.00 (30)	100.00	17.96
Weight Loss	31	22.58	0.00	0.00 (24)	100.00	42.50
Weight Gain	31	25.81	0.00	0.00 (23)	100.00	44.48

Parenthetical values present the frequencies.

Correlational Analyses

CD-RISC and EORTC QLQ-C30. Correlational analysis was initially performed between the CD-RISC total scores and the scale scores for the Global Health Status/QoL Scale, Functional Scales, Symptom Scales, and Single Item Measures on the QLQ-C30 (see Table 13). As can be seen in Table 13, moderate to strong relationships were found between several of the variables.

A positive and strong statistically significant relationship was found between the CD-RISC total scores and the Global Health Status/QoL scale scores ($r=0.615$, $p<0.01$); this

relationship is displayed graphically in Figure 1. The strongest statistically significant correlation between the CD-RISC total scores and the Functional Scales of the QLQ-C30 was identified between the CD-RISC total scores and the Social Functioning Scale ($r=0.669$, $p<0.01$). Comparison of the five Functional Scales with the Global Health Status/QoL scale scores indicated that the strongest statistically significant correlation existed between Global Health Status/QoL and Emotional Functioning ($r=0.652$, $p<0.01$). Among the Symptom Scales and Single Item Measures of the QLQ-C30 the most significant correlation to the CD-RISC was found for the Dyspnea Single Item Measure ($r=-0.638$, $p<0.01$). The strongest correlation was found between the Global Health Status/QoL scale scores and the Pain Scale ($r=-0.560$, $p<0.01$) when just the Symptom Scales and Single Item Measures were considered.

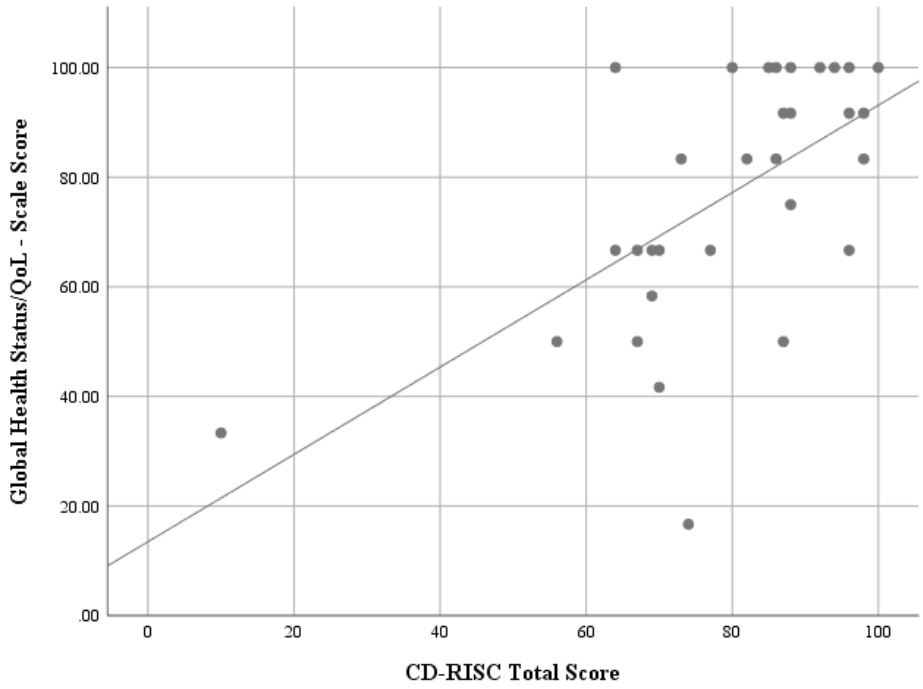

Figure 1. Comparison of Global Health Status/QoL scale scores and CD-RISC total scores.

CD-RISC, Global Health Status/QoL Scale, and EORTC QLQ-H&N35. CD-RISC total scores were also compared with scores for the Symptom Scales and Single Item Measures on the QLQ-H&N35. Table 14 shows the resulting correlational matrix. The strongest statistically significant correlation was found between the CD-RISC total score and the Social Contact Scale ($r=-0.663$, $p<0.01$). Finally, the Global Health Status/QoL scale scores from the QLQ-C30 and the Symptom Scales and Single Item Measures scores from the QLQ-H&N35 were compared to investigate potential relationships (see Table 14). The Nutritional Supplements Single Item scale scores from the QLQ-H&N35 had the strongest correlation with the Global Health Status/QoL scale scores from the QLQ C-30 ($r=-0.676$, $p<0.01$).

Table 13

Correlational Matrix: Comparing Total CD-RISC Scores and EORTC QLQ-C30 Scale scores

	CD-RISC	G HS/QoL	Phys FS	Role FS	Emot FS	Cogn FS	Soci FS	Fati SS	Naus SS	Pain SS	Dysp SI	Inso SI	Appe SI	Cons SI	Diar SI	Fina SI
CD-RISC	1	.615**	.303	.161	.442*	.157	.669**	-.320	-.445*	-.604**	-.638**	-.245	.169	-.006	-.042	-.146
G HS/QoL		1	.503**	.448*	.652**	.380*	.555**	-.529**	-.291	-.560**	-.387*	-.501**	.067	-.048	-.144	-.171
Phys FS			1	.481**	.430*	.460**	.498**	-.485**	-.322	-430*	-.574**	-.519**	-.222	-.229	-.077	-.171
Role FS				1	.669**	.597**	.421*	-.593**	-.259	-.456**	-.348	-.478**	-.011	.019	-.068	-.525**
Emot FS					1	.400*	.735**	-.667**	-.394*	-.700**	-.372*	-.664**	.044	-.239	-.322	-.279
Cogn FS						1	.373*	-.403*	-.512**	-.242	-.312	-.146	-.280	.040	-.065	-.706**
Soci FS							1	-.388*	-.537**	-.717**	-.647**	-.434*	-.169	-.278	-.264	-.258
Fati SS								1	.371*	.759**	.376*	.794**	.055	.016	.240	.276
Naus SS									1	.494**	.543**	.316	.343	.071	.450*	.566**
Pain SS										1	.487**	.696**	.098	.138	.435*	.205
Dysp SI											1	.328	.101	.037	-.027	.232
Inso SI												1	.166	.379*	.331	.070
Appe SI													1	.398*	.306	.232
Cons SI														1	.501**	-.106
Diar SI															1	-.081
Fina SI																1

* p < .05 (2-tailed)

** p < .01 (2-tailed)

Table 14

Correlational Matrix: Comparing Total CD-RISC Scores, Global Health Status/QoL and EORTC QLQ-H&N35 Scale scores

	CD-RISC	G HS/Q	Pain SS	Swal SS	Sens SS	Spee SS	SoEa SS	SoCo SS	Sexu SS	Teet SI	OpMo SI	DrMo SI	StSa SI	Coug SI	FeIl SI	PaKi SI	NuSu SI	FeTu SI	WeLo SI	WeGa SI
CD-RISC	1	.615**	-.154	-.323	.038	-.510**	-.429*	-.663**	-.443*	-.567**	-.205	-.157	-.061	-.076	-.347	-.419*	-.375*	-.108	.152	-.043
G HS/Q		1	-.321	-.386*	-.017	-.503**	-.432**	-.475**	-.393*	-.613**	-.335	-.131	-.162	-.325	-.475**	-.458**	-.676**	-.148	.018	-.260
Pain SS			1	.734**	.367*	.431*	.762**	.344	.311	.638**	.670**	.511**	.689**	.409*	.607**	.165	.407*	.194	.406*	.211
Swal SS				1	.485**	.344	.804**	.404*	.299	.752**	.597**	.322	.595**	.267	.545**	.136	.523**	.473**	.250	.234
Sens SS					1	.165	.287	.171	.041	.254	.262	-.010	.431*	.195	-.025	-.334	.165	.341	-.038	.168
Spee SS						1	.539**	.665**	.443*	.527**	.420*	.396*	.336	.223	.471**	.286	.361*	.039	.036	.125
SoEa SS							1	.631**	.533**	.756**	.616**	.489**	.495**	.416*	.789**	.299	.462**	.172	.434*	.017
SoCo SS								1	.578**	.549**	.302	.206	.131	.075	.421*	.285	.419*	.177	.123	.134
Sexu SS									1	.463**	.263	.336	.194	.119	.479**	.327	.385*	-.027	.095	.122
Teet SI										1	.637**	.339	.532**	.211	.631**	.287	.411*	.355*	.217	.152
OpMo SI											1	.401*	.511**	.188	.827**	.222	.339	.541**	.183	.308
DrMo SI												1	.651**	.231	.481**	.123	.166	-.059	.212	.031
StSa SI													1	.243	.345	-.087	.170	.350	.319	.104
Coug SI														1	.375*	.193	.305	-.213	.040	.058
FeIl SI															1	.417*	.376*	.239	.299	.122
PaKi SI																1	.376*	.239	.299	.224
NuSu SI																	1	.246	-.078	.333
FeTu SI																		1	-.099	.310
WeLo SI																			1	-.319
WeGa SI																				1

* $p < .05$ (2-tailed)

** $p < .01$ (2-tailed)

Observational Analyses

Sex. Initially, Mann-Whitney U-tests were performed to compare potential differences in male and female participants' CD-RISC total Scores and Global Health Status/QoL scale scores. No statistically significant difference was observed for either comparison. Sex was then graphed against the CD-RISC total scores and against the Global Health Status/QoL scale scores (Figure 2 and Figure 3, respectively). Although females only represented 25.8% of the sample, Figures 2 and 3 cautiously suggest that their CD-RISC total scores and Global Health Status/QoL scale scores tended to be higher.

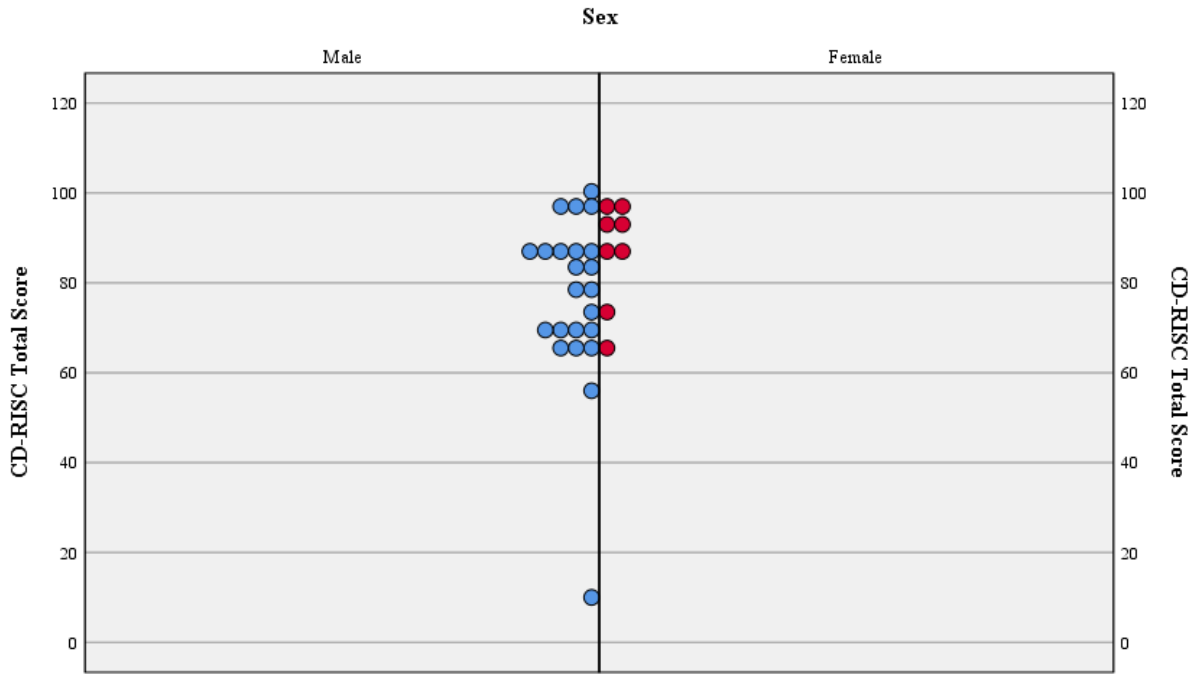

Figure 2. Comparison of CD-RISC total scores and sex.

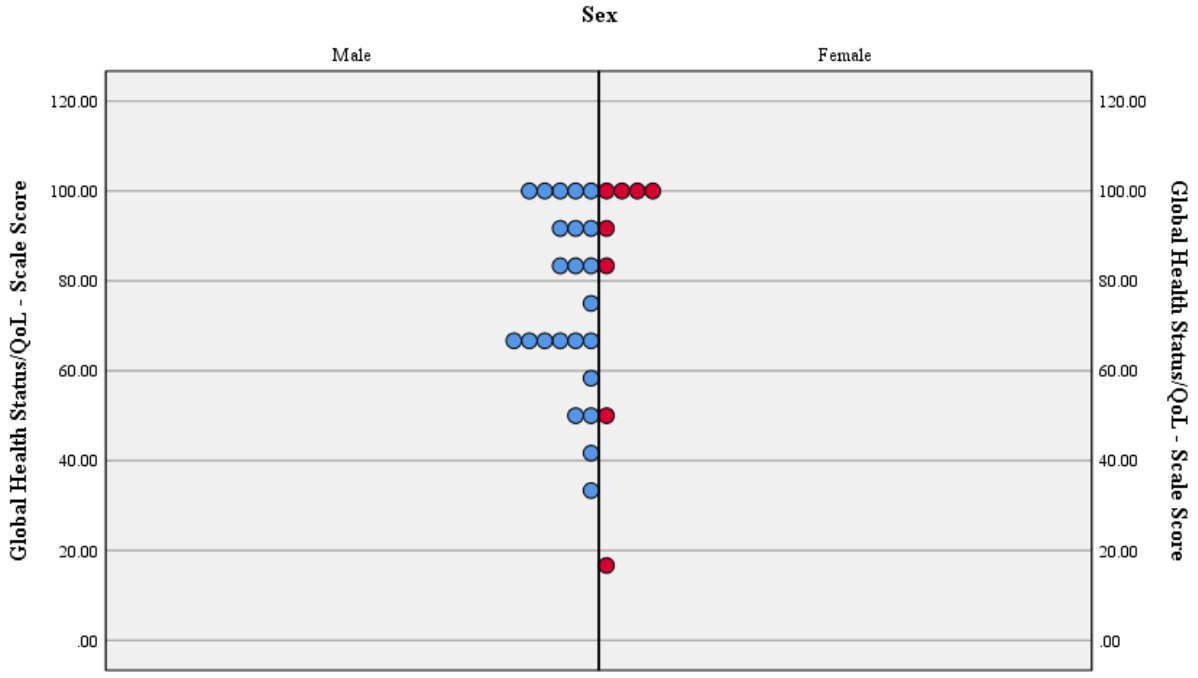

Figure 3. Comparison of Global Health Status/QoL and sex.

Age. Correlational analysis of both CD-RISC total scores and Global Health Status/QoL scale scores with age did not reveal a statistically significant relationship. However, when raw data for the CD-RISC are graphed against participant age, a slight negative slope can be observed. When Global Health Status/QoL scale scores are graphed against age, a negative slope also exists. Figures 4 and 5 display comparisons of CD-RISC total scores and Global Health Status/QoL scale scores with age, respectively.

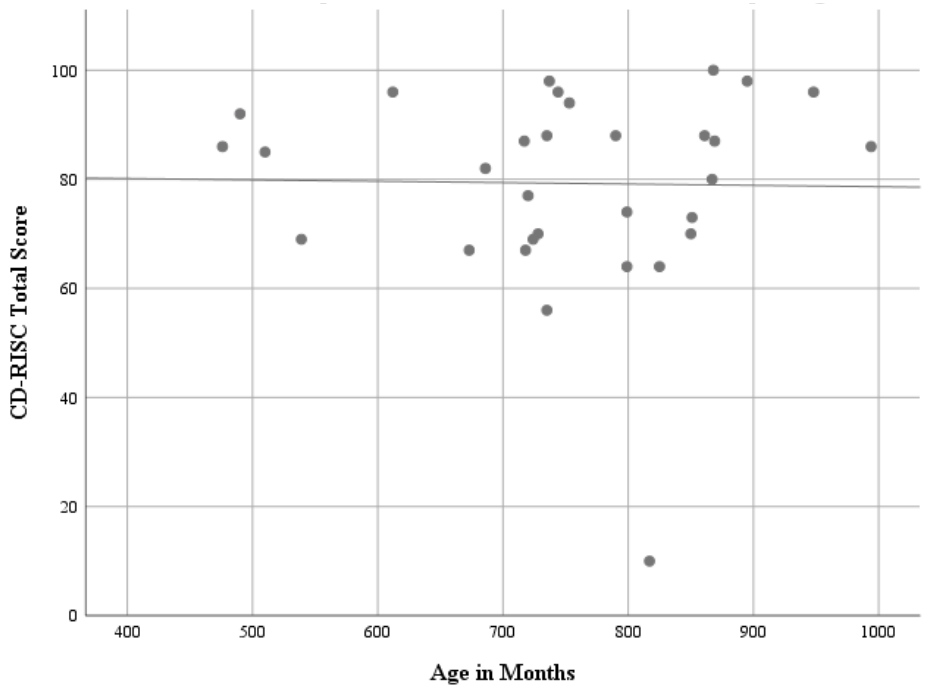

Figure 4. Comparison of CD-RISC total scores and participant age.

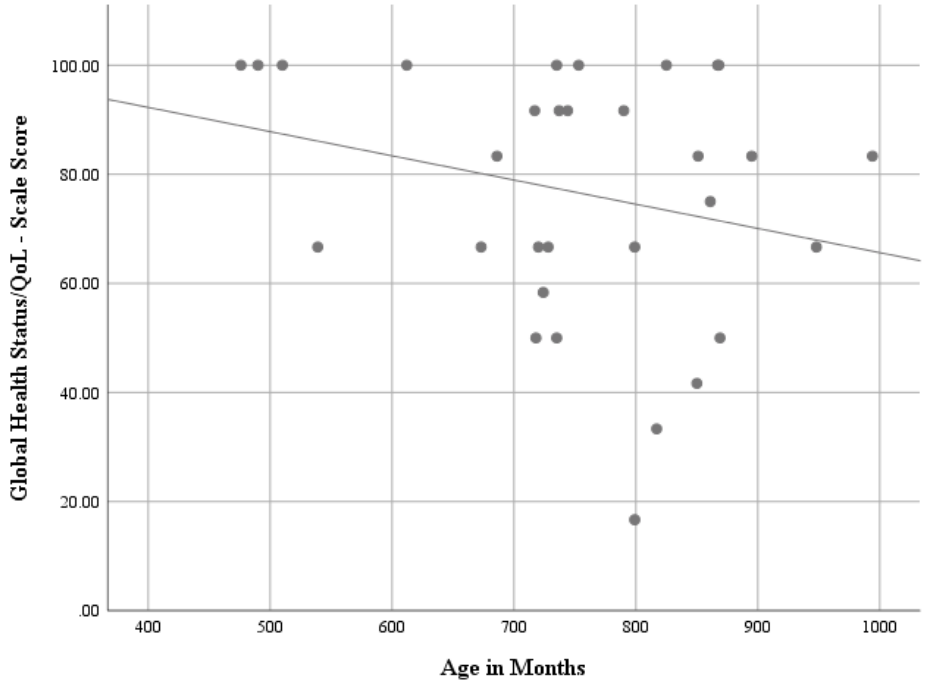

Figure 5. Comparison of Global Health Status/QoL scale scores and participant age.

Site of cancer. Figure 6 displays the site of cancer graphed against CD-RISC total scores. Based on visual analysis, no clear trend exists between these factors. The site of cancer is graphed against the scale scores for Global Health Status/QoL in Figure 7. Similarly, no clear visual trend is observable between cancer site and Global Health Status/QoL scale scores.

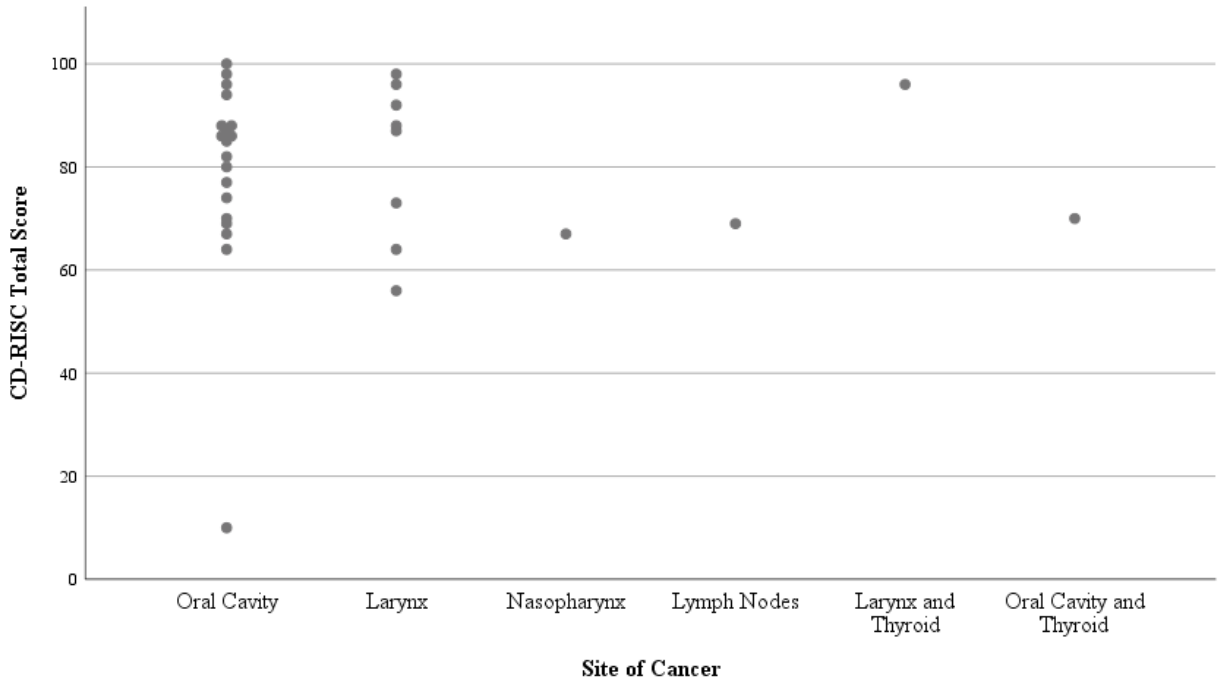

Figure 6. Comparison of CD-RISC total scores and site of cancer.

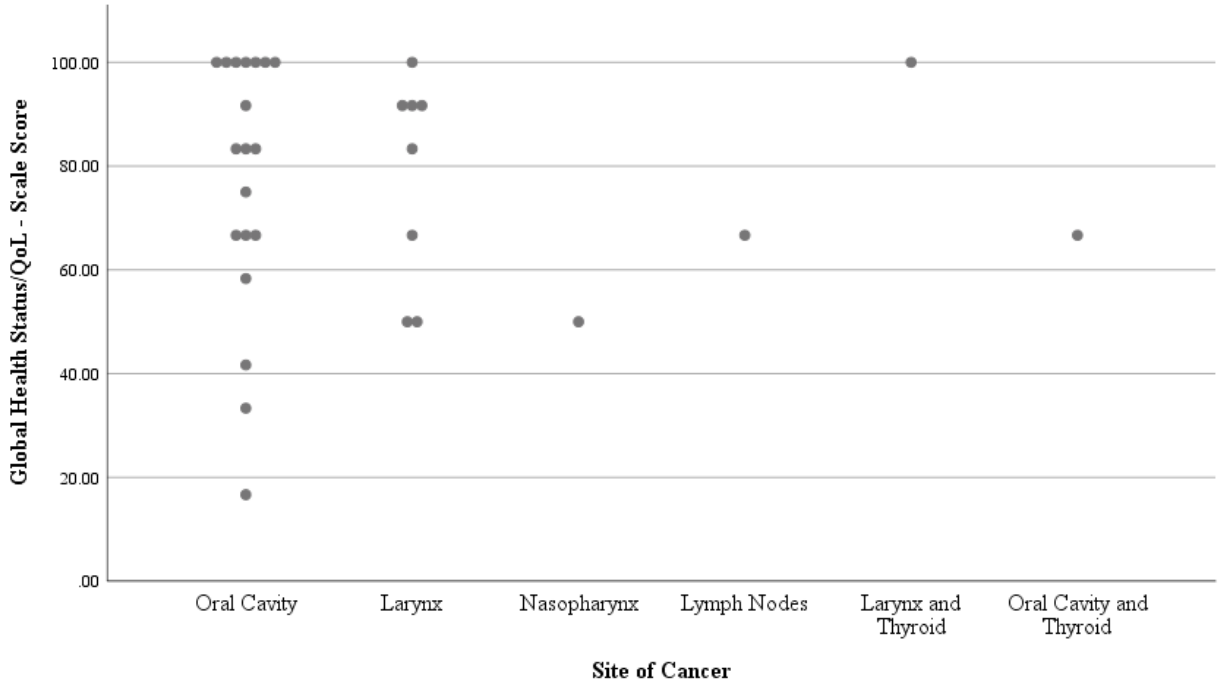

Figure 7. Comparison of Global Health Status/QoL scale scores and site of cancer.

Clinical stage of cancer. Figure 8 displays the clinical stage of cancer graphed against the CD-RISC total scores. No visible trend is present. Figure 9 displays the clinical stage of cancer graphed against the scale scores for Global Health Status/QoL and, again, no visual trend is observable.

Figure 8. Comparison of CD-RISC total scores and clinical stage of cancer.

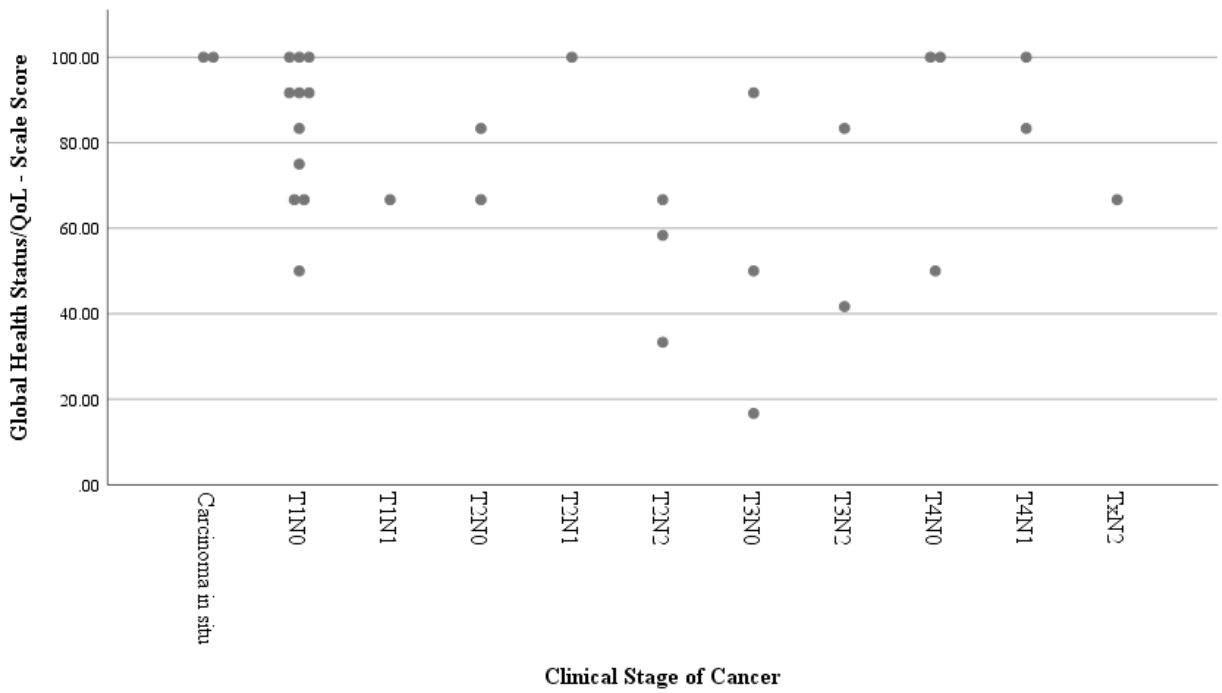

Figure 9. Comparison of Global Health Status/QoL scale scores and clinical stage of cancer.

Treatment modality. Figure 10 displays treatment modality graphed against participant total scores for the CD-RISCs. Based on visual analysis, two natural groups are apparent: those who received surgery alone and those who received surgery and radiation therapy. Visual comparison of these groups suggests similar levels of resilience (see Figure 10). Treatment modality was also graphed against the scale scores for Global Health Status/QoL (see Figure 11). Once again, two treatment modality groups are present and, similarly, the group of individuals who received surgery alone and the group that received surgery and radiation therapy display very similar levels of perceived QoL.

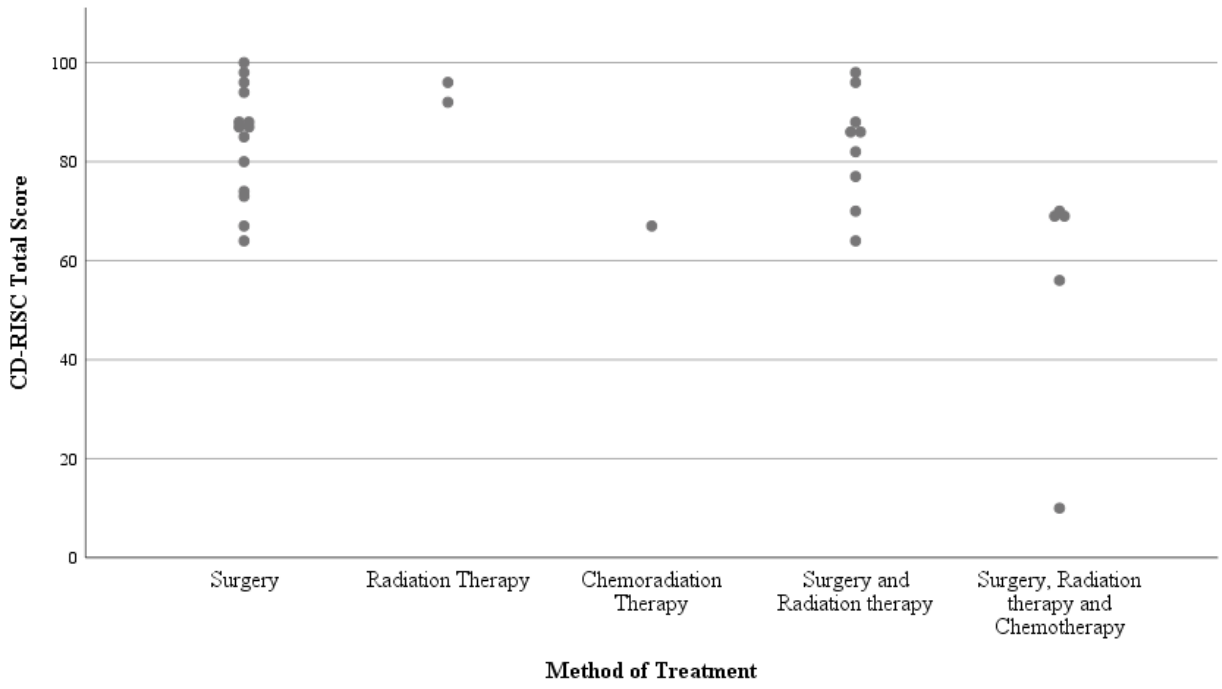

Figure 10. Comparison of CD-RISC total scores and treatment modality.

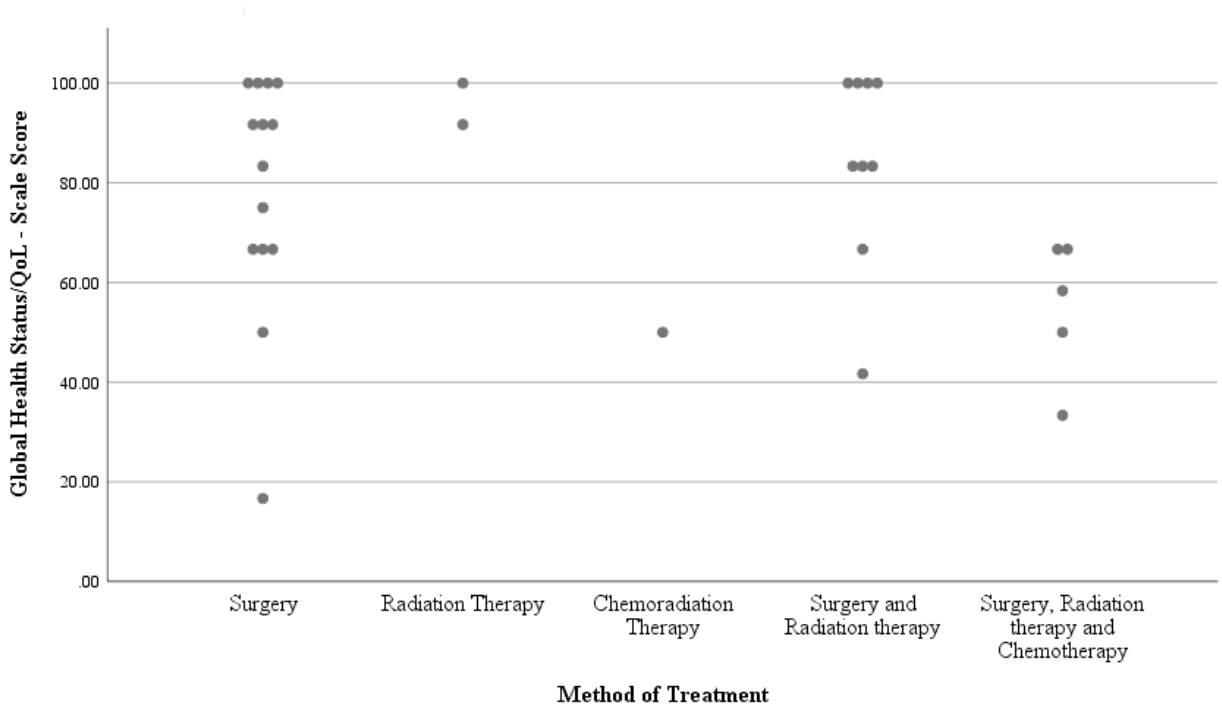

Figure 11. Comparison of Global Health Status/QoL scale scores and treatment modality.

Time since diagnosis. When the CD-RISC total scores were graphed against time since diagnosis (in months), a positive slope can be observed (Figure 12). When Global Health Status/QoL scale scores are graphed against time since diagnosis, a slight decline in Global Health Status/QoL scale scores with increasing time is suggested (Figure 13).

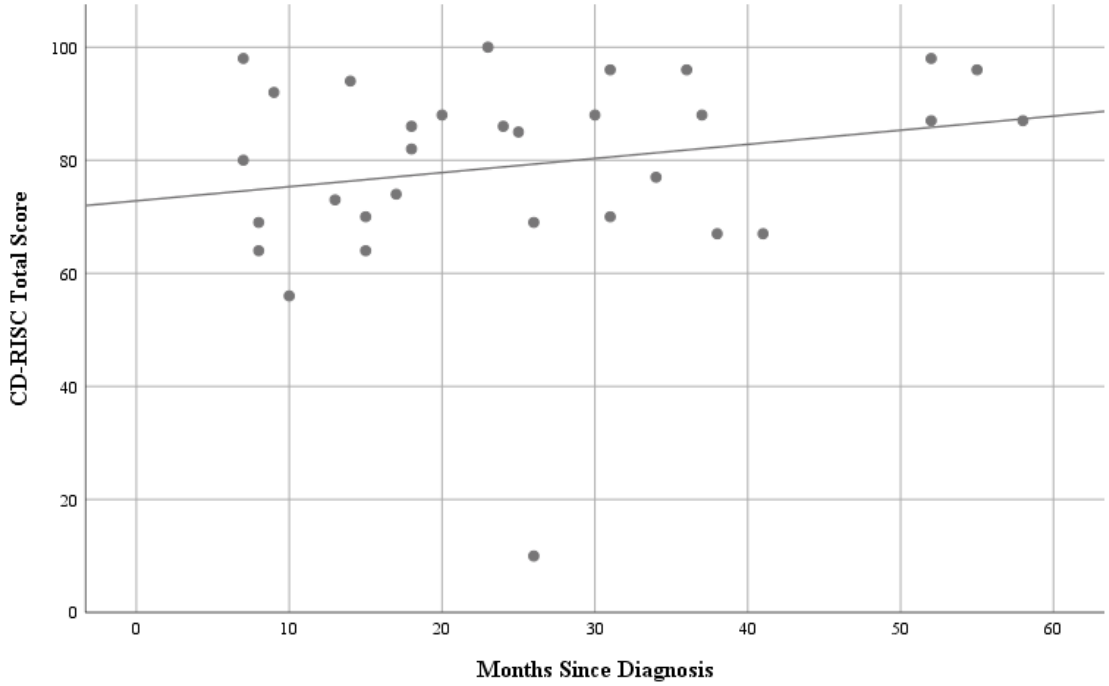

Figure 12. Comparison of CD-RISC total score and months since diagnosis.

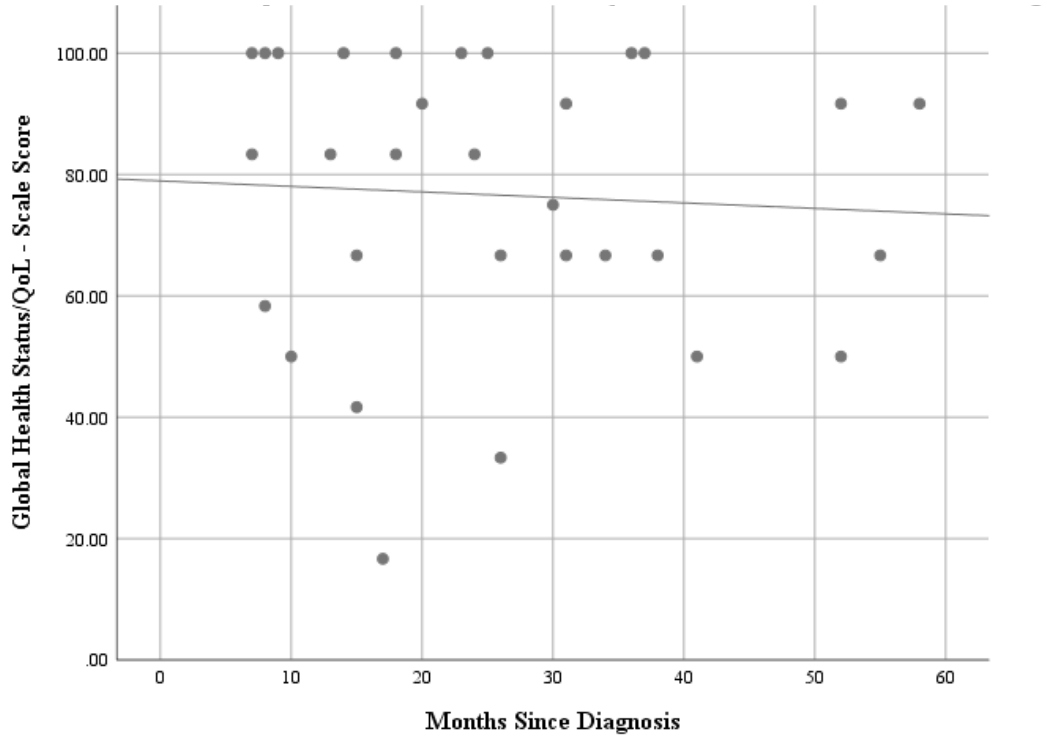

Figure 13. Comparison of Global Health Status/QoL scale scores and months since diagnosis.

Time since treatment completion. A positive slope can be observed when CD-RISC total scores are graphed against time since treatment completion (in months) (Figure 14). When Global Health Status/QoL scale scores are graphed against time since treatment completion, the data suggest a slight decline in Global Health Status/QoL scale scores with increasing time post-treatment (Figure 15).

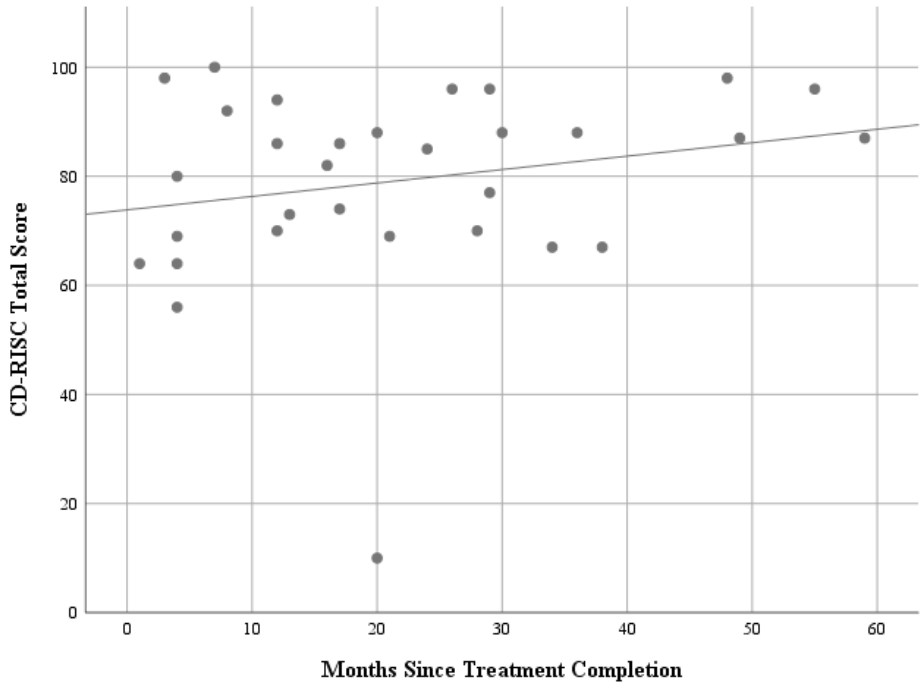

Figure 14. Comparison of CD-RISC total scores and months since treatment completion.

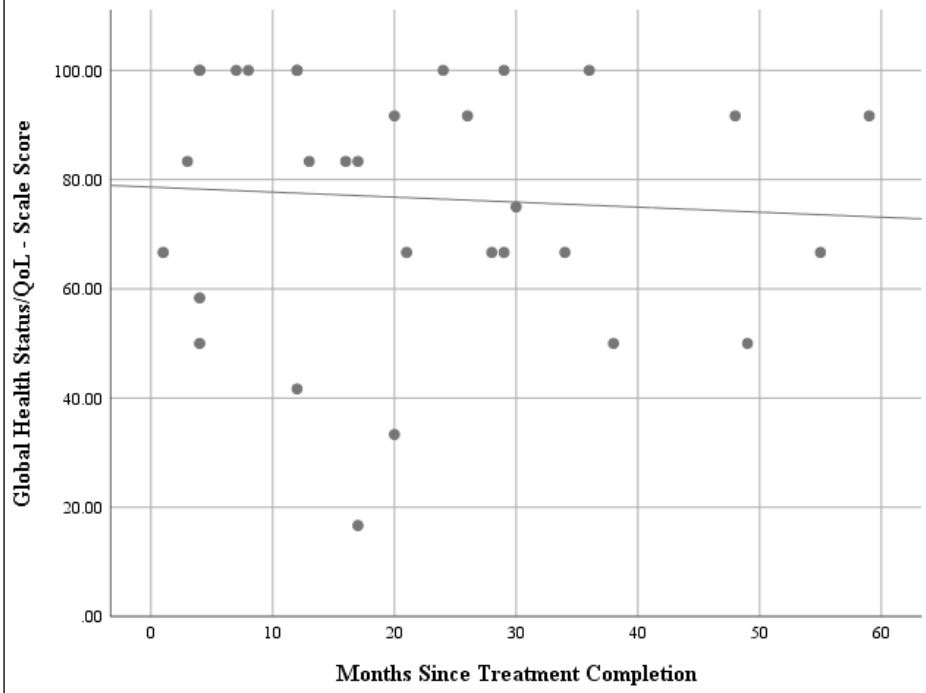

Figure 15. Comparison of Global Health Status/QoL scale scores and months since treatment completion.

CHAPTER 4

Discussion

This study was designed to identify the presence of resilience in individuals who had completed treatment for HNCa and to explore the potential relationship between resilience and QoL. Thus, the primary aim of the study centred on the identification of resilience in HNCa survivors. This study also sought to identify the potential role of resilience in buffering the adverse impact of HNCa and its treatment on QoL. Accordingly, the specific objectives of the study were to:

1. Identify the presence of resilience in a sample of individuals who had completed curative treatment for HNCa and,
2. Determine if a relationship exists between individuals' resilience and QoL in the context of their survivorship experience with HNCa.

In the pursuit of fulfilling these study objectives, data pertaining to resilience and QoL were collected using the Connor-Davidson Resilience Scale (CD-RISC), European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), and European Organisation for the Research and Treatment of Cancer Head and Neck Cancer Module (EORTC QLQ-H&N35). The two EORTC questionnaires also provided data on areas of functioning and groupings of symptoms that are pertinent to HNCa survivors and their valuation of QoL. In the sections to follow, a comprehensive discussion of the findings from the CD-RISC, EORTC QLQ-C30, and EORTC QLQ-H&N35 will be presented. This will be followed by a discussion of relationships identified between the measures. Observational analyses of demographic data (e.g., sex, age, site of cancer, clinical stage of cancer, treatment modality, time since diagnosis, and time since treatment completion) and resilience and global QoL will

subsequently be discussed. Finally, limitations of the present study, clinical implications of the findings, and directions for future research will be offered.

CD-RISC

In order to quantify the presence of resilience, the CD-RISC was developed (Connor & Davidson, 2003). The CD-RISC consists of 25 items that are summed to generate a total score that represents the quantified level of resilience, where higher scores reflect greater levels of resilience (Davidson & Connor, 2016). Since no clinically significant score has been established by the authors of the CD-RISC, a total score of 50 was arbitrarily selected to demarcate those participants with a lower level of resilience from those with a higher level. More specifically, participants who scored below 50 were identified as minimally resilient, while participants who scored 50 and above were identified to be more highly resilient. Descriptive statistics for the CD-RISC indicated that on average, the vast majority of participants (96.8%) scored above the arbitrary threshold score of 50; thus, the overall data obtained tended to reflect higher levels of resilience (mean = 79.3, SD=17.7). Thus, resilience was indeed identified in the present study's sample of HNCa survivors.

Interestingly, among the 25 items on the CD-RISC, item 25 was agreed with most, since on average, participants considered taking pride in one's achievements to be true nearly all the time (mean = 3.52). Item 3 was the least agreed with item; participants tended to consider relying on fate or God to help with problem solving rarely to be true (mean = 2.23). Nonetheless, participants' level of agreement with item 3 also was quite varied (SD = 1.69, range = 4), indicating that the presence or absence of some form of spirituality may have an individualized influence on one's approach to solving problems. Identification of domains that may contribute to resilience, as indicated by resilient individuals' responses to items on the CD-RISC, may serve

to inform potential targets for interventions that aim to foster resilience (e.g., encouraging recognition of past successes or achievements) in unique populations, such as HNCa survivors.

The data on overall resilience in HNCa survivors suggest that those who have completed treatment have resilience scores that are similar to normative comparative samples for the CD-RISC that were developed with a general population sample (Connor & Davidson, 2003). This comparative sample provided a mean total score of 80.4 on the CD-RISC (SD=12.8, n=577) (Connor & Davidson, 2003). Interestingly, the similarity between the mean total scores of resilience in the sample of the general population and the present sample of HNCa survivors suggests that HNCa does not uniquely influence resilience, but just acts as an event of sufficient adversity that triggers resilience. Therefore, it may be suggested that the disablement experience of HNCa does not distinctively modify the level of resilience of those individuals who have completed treatment. In essence, despite different encounters of adversity throughout the lifespan (i.e., encountering the disablement experience of HNCa), the interactive process of protective and risk factors at intrapersonal and environmental levels still yields a comparative level of resilience in those who have experienced HNCa compared to those who have not.

Consideration of previously reported CD-RISC mean total scores from studies carried out in patient groups with a variety of cancers and at various time points throughout the clinical pathway is also relevant. The mean total score of resilience in the present sample of individuals who had completed treatment for HNCa is somewhat elevated from the levels of resilience reported in previous studies. For instance, in a study by Dubey, De Maria, Hoeppli, Betticher, and Eicher (2015) the CD-RISC was administered to a sample of male and female cancer patients in Switzerland (n=68, mean age=63.2). The participants in their study were in the early stages of treatment (4-15 weeks since diagnosis) for a variety of cancers, in which HNCa (n=5)

was included as a subgroup. The mean total score was reported to be 74.4 (SD=12.6) among the entire sample that included the various tumour sites and 68.2 (SD=14.8) for the HNCa subgroup. Additionally, in a randomized pilot clinical trial conducted by Loprinzi, Prasad, Schroeder, and Sood (2011) the effect of a stress management and resilience training program was assessed in a sample of breast cancer survivors (n=20, mean age=61) in the United States. Prior to the commencement of the training program, baseline mean total scores for the CD-RISC were reported to be 73.6 (SD=10.1) and 78.2 (SD=12.6) for the individuals assigned to the active arm (n=12) and control arm (n=8), respectively. It can be noted that an increase in CD-RISC total scores was observed following the completion of their training program. However, given the objective of the present study, comparison is only warranted with the baseline levels of resilience reported in the study by Loprinzi et al. (2011).

Upon comparison between the mean resilience score found in the present study and the means reported in previous studies, it is evident that variation exists in the level of resilience in individuals who have been diagnosed with cancer. However, upon careful consideration, perhaps the varied time points at which resilience was measured and quantified in the previous studies limits the ability to fully generalize the previous findings to those of the present study. More specifically, Dubey et al. (2015) measured participants' resilience levels in the early stages of their treatment; in contrast, the present study was interested in the presence of resilience *after* participants had completed active treatment. Although the participants in the study by Loprinzi et al. (2011) were diagnosed with breast cancer, both their study and the present study utilized the CD-RISC to measure resilience after treatment completion. Thus, the similarity in the timing of the measurement of resilience may render the mean resilience scores more comparable. Therefore, when the study designs are taken into account (i.e., comparable time reference and

"n" value), the mean resilience score found in the present study (79.3) is consistent with the level of resilience reported by Loprinzi et al. (2011).

Given the variability of CD-RISC scores among those involved in the present study (range = 10-100, SD=17.7), it is apparent that resilience is highly individualized. That is, each individual will have encountered different life events, including different developmental experiences during childhood and different protective and risk factors during adulthood. Ultimately, these different life experiences may influence the position of the proverbial fulcrum in the resilience balance scale. Although the current inclusion and exclusion criteria were stipulated in an attempt to limit extraneous diversity within the sample, it was impossible to screen out all individual differences that may influence resilience (e.g., past experience coping, and factors of child development that contribute to emotional regulation and executive functioning). The effect of individual differences on resilience, as measured with the CD-RISC, could have been exaggerated due to the small sample size and the fact that convenience sampling was employed. However, despite the potential influence of individual differences on resilience, the mean resilience score found in the present study (79.3) is still consistent with the resilience score found in the aforementioned comparable study (78.2) (Loprinzi et al., 2011).

EORTC QLQ-C30

Due to the potential biopsychosocial challenges that may result secondary to HNCa and its treatment, a central objective of the present study was to investigate perceived QoL, both globally and in relation to various domains of functioning and symptoms recognized to be potentially disabling to those with cancer. The 30 items of the QLQ-C30 address common concerns of cancer patients. Following linear transformation of the raw scores, the data from each item are categorized into Functioning Scales, Symptom Scales, Single Item Measures, and a

Global Health Status/QoL Scale. The resultant QLQ-C30 data may then be used to summarize individuals' multifaceted disablement experience secondary to their cancer.

First, participants' responses to the 30 items of the QLQ-C30 suggest that the majority rarely, if at all, experienced the challenges and concerns addressed by the questionnaire. However, participants reported the greatest level of challenge with question 11, which asks "Have you had trouble sleeping?". This was consistent with the responses to the Symptom Scales and Single Item Measures; the Insomnia Single Item Measure was found to represent the participants' highest reported level of symptomology or challenge. The findings of the present study are in line with previous studies conducted by Duffy et al. (2008) and Shuman et al. (2010) who found that sleeping problems are a common issue for HNCa survivors. Furthermore, Irwin (2013) reported that insomnia can continue into extended survivorship, a finding that is also in line with those of the present study. Interestingly, Irwin (2013), Shuman et al. (2010), and Duffy et al. (2008) posit that insomnia experienced by HNCa survivors may be attributable to psychological sequelae associated with the disease and its treatment, such as depression, distress, and anxiety. Since these psychological challenges are characteristic of those experienced by HNCa survivors (Bornbaum et al., 2012; Cohen et al., 2015; Howren et al., 2012), the finding that participants experienced a high degree of challenge with sleeping problems is understandable.

Accordingly, among the Functional Scales, participants reported the lowest level of functioning in the emotional domain. The Emotional Functioning Scale reflects items that ask if the individual has felt tense, has worried, been irritable, and/or felt depressed (questions 21-24). As such, it is notable that the diagnosis of HNCa is associated with a higher prevalence of depression when compared to the rates of depression among other oncological populations

(Howren et al., 2012). In addition to depression, substantial disruption to psychological functioning is also evidenced by a high representation of worry and anxiety in HNCa survivorship populations (Cohen et al., 2015; Stanton et al., 2015). Interestingly, among the four items that factor into the QLQ-C30 Emotional Functioning Scale, questions 22 ("Did you worry?") and 24 ("Did you feel depressed?") indicate that participants felt worried and depressed to a greater degree than they experienced the concerns alluded to by questions 21 ("Did you feel tense?") and 23 ("Did you feel irritable?"). As such, the findings pertaining to depression, anxiety and emotional functioning are consistent with the published literature (Cohen et al., 2015; Howren et al., 2012; Stanton et al., 2015).

In addition to the low scores reported for the Emotional Functioning Scale, participants from the present study reported an equally low average level of functioning in the Social Functioning Scale. Correspondingly, an individual's inhibited ability to communicate and capacity to engage socially is commonly linked with psychological dysfunction (e.g., depression) (Howren et al., 2012), which was also reported by the participants of the present study. Thus, the interdependent and multidimensional nature of the functional deficits experienced by HNCa survivors is highlighted. The diminished social functioning reported by participants is of particular concern since it has been well established that finding support through social interaction is correlated with positive adjustment to one's experience of disease (McDonough et al., 1996). Analogously, it follows that social support and functioning is also of relevance to resilience which is congruent with the findings of the present study.

The concurrent identification of elevated dysfunction in the domains of emotional and social functioning also speaks to the reality of the notion that the psychosocial impact of survivorship is commonly more challenging than the direct effects of physical treatment sequelae

(Wolff, 2007). Furthermore, the fact that the participants ranged from 1 to 59 months post treatment and, thus, were in the extended phase of survivorship, is in line with the notion that extended survivorship is commonly associated with psychosocial burden (Stanton et al., 2015). Thus, after the objective biological aspects of the disease have been resolved, suffering related to the subjective dimensions of disablement remains and may be difficult to overcome (Ueda & Okawa, 2003). Since the subjective psychosocial consequences of the disease may be more challenging to surmount than the physical aspects, diminished coping and adjustment may occur secondary to unresolved suffering in the psychosocial domain of disablement (McDonough et al., 1996).

In relation to the psychosocial dysfunction reported by the participants, it is interesting to note that 96.8% of the sample of HNCa survivors were found to be highly resilient. Given the concurrent presence of both resilience and psychosocial dysfunction, this finding supports the notion that highly resilient individuals are not immune to negative emotions or risk factors (Markovitz et al., 2015; Molina et al., 2012). As such, the results of the present study mirror the notion that resilience is a process whereby protective factors may act to buffer risk factors, but they do not eliminate them (Werner, 2000). Instead, it appears that resilience may allow the individual to deal more effectively with stressors that may cause emotional disturbance. This observation may be supported by the finding that although participants reported the lowest levels of functioning in emotional and social domains, the quantified level of dysfunction was not to an extreme (i.e., the scale scores for emotional and social functioning were 86.02; a score of 100 denotes no perceived functional challenge). Thus, since no causal relationship can be concluded from the present study, delineating the nature of the interaction between resilience and HNCa survivors' experience of dysfunction and symptomology warrants further study.

Furthermore, in addition to reporting minimal levels of dysfunction and symptomology, the current participants also reported nearly optimal levels of QoL. In light of the findings of the CD-RISC, the role of the quantifiably high level of resilience in ameliorating the participants' perceptions of their experience of dysfunction and symptomology, and, in turn, buffering the influence of the potential challenges of HNCa and its treatment on perceived QoL can be called to question. However, it is important to note the relationship that exists between resilience and QoL may simply be characterized as coexistent. To provide additional information that may serve to contextualize the relationship between resilience and QoL in HNCa survivors specifically, the EORTC QLQ-H&N35 was employed.

EORTC QLQ-H&H35

To supplement the QLQ-C30 core questionnaire, the QLQ-H&N35 was also utilized to gather information pertaining to areas of concern specifically for individuals diagnosed with HNCa. The items of the QLQ-H&N35 are intended to cover the HNCa disablement experience by addressing issues pertaining to disease and treatment related symptoms and side effects, as well as issues associated with social function and sexuality. By extension, the items on the QLQ-H&N35 should cover symptomology that are pertinent to participants of the present study. However, the majority of participants indicated that they did not experience the symptoms addressed by this HNCa specific module. The exception to this general trend can be observed through the markedly higher mean score of question 11, which asks "Have you had a dry mouth?". Accordingly, the most commonly reported challenge associated specifically with HNCa and its treatment as quantified by Symptom Scales and Single Item measures of the QLQ-H&N35, was the Dry Mouth Single Item Measure. In line with the findings of the present study,

the perception of dryness in the oral cavity, or xerostomia, commonly occurs secondary to radiation and/or chemotherapy (Marur et al., 2016).

Xerostomia could be considered an overtly medical and primarily physiological health condition; however, from a biopsychosocial perspective, xerostomia may also heavily influence social functioning. For instance, since the sensation of a dry mouth commonly augments the burden of dysphagia (Pauloski, 2008), xerostomia is a physical consequence of HNCa treatment that may limit one's ability to engage in shared meal times in social settings which may then result in social isolation (Pateman et al., 2015; Threats, 2007). Thus, results of the QLQ-H&N35 may be viewed as complimentary to the findings of the QLQ-C30 that found that some participants experienced elevated levels of dysfunction in the social domain. Furthermore, given the concurrent identification of participants' experience of physical symptomology (dry mouth) and social dysfunction, the interrelated and multifaceted nature of the functional deficits experienced by HNCa survivors is apparent in the results of the present study. Ultimately, this finding suggests that it is important to approach the concerns of HNCa survivors through a biopsychosocial lens, as to not be blinded to the potential influence of one concern on a wide array of additional domains of functioning. Thus, consideration of relationships that may exist among the multitude of challenges faced by HNCa survivors and resilience and QoL warrants further discussion.

Correlational Analyses

Resilience and QoL. Based on findings from correlational analysis it was determined that a strong and statistically significant positive relationship exists between resilience scores and global QoL scores. As such, this positive relationship suggests that as individuals' resilience increases, their perceived QoL also increases, whereby the level of resilience is indicated by

higher total scores on the CD-RISC and perceived QoL is illustrated by higher scale scores on the Global Health Status/QoL Scale on the QLQ-C30.

Conceptually, the positive relationship found between resilience and QoL is not a surprising finding. Resilience is understood to be the process of positive adaptation in the pursuit of homeostatic functioning in physical, psychological, and social domains in the context of adverse circumstances (Gillespie et al., 2007; Pieters, 2016). Somewhat congruently, QoL denotes an individual's perception of his or her physical, psychological, and social functioning and well-being (WHO, 1997). If positive adaptation occurs within the domains of functioning, perceived changes to QoL could be expected. It follows conceptually that resilience, at a minimum, may directly influence the psychosocial aspect of QoL, and may mediate the relationship between the HNCa disablement experience and survivors' QoL (Tian & Hong, 2014; Wu et al., 2015). This suggests that resilience may play a protective role in buffering the adverse influence of the HNCa disablement experience on QoL. It is important to note, however, that the positive relationship identified between resilience and QoL does not suggest causal interaction, but rather, that the two constructs vary together.

While numerous studies have explored QoL in HNCa survivors, limited data exist on the presence of resilience in this unique population. Consequently, little evidence has served to elucidate the relationship between resilience and QoL in the context of an individual's experience with HNCa. That being said, the findings of the present study are consistent with those of Tian and Hong (2014). In their study, Tian and Hong (2014) reported that a relationship existed between resilience and QoL in individuals diagnosed with digestive cancer; however, they stated that the nature of this relationship was not fully understood. Additional research will be required to further delineate this relationship. In addition to the relationship found between

resilience and QoL in the present study, a number of other relationships were identified between resilience, QoL, and various domains of functioning and symptomology. These relationships will be discussed in the sections to follow.

Resilience and social functioning. Strong, statistically significant relationships were found between resilience and scales that measured various aspects of social functioning, namely, the Social Functioning Scale ($p<0.01$) from the QLQ-C30, and the Social Contact ($p<0.01$) and Social Eating Symptom Scales ($p<0.05$) from the QLQ-H&N35. In light of the substantial challenges a HNCa survivor may face in the social domain of functioning, the identification of a relationship between social functioning and resilience becomes particularly intriguing.

The correlation between resilience and the Social Functioning Scale was characterized as a positive relationship, while the correlations between resilience and the Social Contact and the Social Eating Symptom Scales were found to be inverse relationships. The conflicting positive and negative relationships become logical upon consideration of the difference in interpretation of the Functioning Scale Scores on the QLQ-C30 and the Symptom Scale Scores on the QLQ-H&N35; a high score on a functioning scale denotes a better level of functioning, whereas a high score on a Symptom Scales indicates a greater perceived level of challenge or problem in the scale's content area. Thus, the statistically significant positive relationship found between resilience and social functioning suggests that as individuals' levels of resilience increase, their social functioning also improves. Accordingly, the statistically significant inverse relationship found between resilience and challenges with social contact and social eating implies that as HNCa survivors' resilience *decreases,* they experience greater challenge in terms of their experience with social contact and social eating.

Upon review of the literature, it is apparent that the connection found between resilience and social functioning in the present study is consistent with past research. Connor and Davidson (2003) include "engaging the support of others" (p. 77), as a salient characteristic of resilience. The ability to seek social support from others is intrinsically integral to an individual's healthy social functioning. Thus, it follows logically that resilience would be positively correlated to social functioning and negatively correlated to a high degree of trouble with social contact. Additionally, Dubey et al. (2015) cite strong social support systems that may include family members, significant others, and peers as central protective factors that are fundamental to resilience. Given previous findings in published literature and the findings of the present study, it appears that individuals' capacity for strong social functioning interacts with their resilience; however, the causality of this interaction remains unknown and, in actual fact, the two factors may simply vary together.

While causal relationships cannot be concluded from the results of the present study, it is difficult to ignore the potential link to the foundational development of resilience that occurs during childhood. More directly, as part of the foundation that is laid during childhood, the single most common variable that predicts the development of resilience is the presence of a secure and supportive relationship (National Scientific Council on the Developing Child, 2015). This finding suggests the inverse relationship between resilience and challenges with social functioning exist throughout the lifespan. For instance, starting in the formative years of childhood, the higher the level of social challenge experienced, the lower the level of resilience. Thus, it may be speculated that the identified relationship may illustrate that social dysfunction acts to threaten the development and/or expression of resilience, however, it may also illustrate that resilience acts to buffer the experience of social dysfunction. It is important to note that a

third explanation may exist; the relationship may simply illustrate that resilience and social functioning vary together. Ultimately, the precipitating factor in this relationship cannot be determined from the results of the present study. However, it is apparent that a relationship exists between strong and healthy social functioning and one's ability to be resilient.

It is also interesting to note an additional area of concern identified by the QLQ-H&N35 that is observationally connected to HNCa survivors' capacity to function socially and, thus, may influence their resilience. A moderately significant negative correlation was identified between the Speech Symptom Scale and both resilience and QoL. Given the central role of verbal communication in social interaction, speech and voice deficits are widely accepted to impair social functioning (Eadie et al., 2015). The conspicuous nature of speech and voice deficits that are associated with HNCa and its treatment, has been well documented to precipitate impaired social functioning and the potential for social isolation (Doyle, 2005; Howren et al., 2012; Semple et al., 2004). Furthermore, the resultant social dysfunction and the potential for perceived stigma of not conforming to social norms, interact innately with perceived QoL (Doyle, 2005; Howren et al., 2012; Semple et al., 2004). Nevertheless, social dysfunction is just one of the many issues that may influence the QoL of a HNCa survivor. Thus, consideration of the relationships found between QoL and functional domains is of relevance.

QoL and functional domains. By definition, QoL is a multidimensional construct. The HNCa survivorship experience has the potential to influence the biopsychosocial dimensions that may be central to a survivor's valuation of his or her QoL. This sentiment is mirrored by the findings of the present study which suggest that each of the five domains of functioning covered in the QLQ-C30 had strong-to-moderate positive relationships with global QoL. In addition to the multidimensionality of QoL, the interdependent nature of the domains that may contribute to

QoL was also observed. That is, the positive significant relationships that were also found between all five domains of functioning alludes to the reciprocal nature of their mutual connections. Among the five domains, Emotional Functioning was found to have the strongest correlation to global QoL. This finding is complementary to the previously stated findings of the present study that indicated that emotional functioning is a salient issue experienced by HNCa survivors. The correlation found between QoL and emotional functioning is also consistent with previous studies that have reported that emotional functioning has a well-documented relationship with survivors' valuation of QoL (Carlson & Bultz, 2004).

In light of the correlations found between resilience and social functioning, it is interesting to note that the Social Functioning Scale had the second highest correlation with QoL. The Social Contact Symptom Scale and the Social Eating Symptom Scale on the QLQ-H&N35 were also found to be significantly correlated with QoL. Similar to the relationships identified with resilience, a positive correlation was revealed between the Social Functioning Scale and QoL, while negative correlations were found between the two Symptom Scales and QoL. Collectively, these data suggest that as social functioning increases and challenges pertaining to social eating and contact decrease, a HNCa survivor's QoL increases.

Resilience, QoL, and symptomology. The strongest correlation found among resilience and the Symptom Scales and the Single Item Measures of the QLQ-C30 was an inverse relationship between resilience and dyspnea. While it is not readily apparent how dyspnea is related to resilience, the negative relationship found between this physical sequela of HNCa and resilience cannot be overlooked. While the causal nature of this relationship is unknown, the experience of dyspnea may represent a risk factor that acts to shift the equilibrium of the survivor's proverbial resilience balance scale towards negative outcomes. As such, the findings

of the present study indicate that as one's challenge with dyspnea increases, resilience decreases. The interaction between dyspnea and resilience may also have something to do with the other significant inverse relationships identified between dyspnea and physical, social, and emotional functioning. Since it was found that as dyspnea increases, physical, social, and emotional functioning decrease, the cumulative impact of the experience of difficulty breathing on survivors' functioning may ultimately shed light on the interaction between dyspnea and resilience.

Additionally, the QLQ-C30 symptom scale that represents an individual's experience of pain was found to have strong-to-moderately significant inverse relationships with both resilience and QoL. While it is not surprising that as a HNCa survivor's experience of pain increases, his or her resilience and QoL may decrease, what is interesting is that pain was found to correlate with many other areas of functioning that may not be initially obvious. While pain is correlated with resilience and QoL, significant negative correlations were also found between pain and domains of physical, role, emotional, and social functioning, in addition to significant positive correlations between pain and the experience of fatigue, nausea, dyspnea, insomnia, and diarrhea. Once again, the highly interrelated and multidimensional nature of the myriad challenges potentially experienced by HNCa survivors may be observed through the relationships found in the present study. Thus, not only is pain known to impact at least half of individuals with HNCa (Howren et al., 2012), the experience of pain extends its extremely broad influence to envelop the multitude of functional domains included on the QLQ-C30. Therefore, the importance of monitoring pain in HNCa patients cannot be overstated (Howren et al., 2012).

While the identification of a significant negative correlation between fatigue and QoL is consistent with previous studies (Carlson & Bultz, 2004; Romito, Montanaro, Corvasce, Di

Bisceglie, & Mattioli, 2008; Scott, 2015; Visser & Smets, 1998), it is of particular interest to note that fatigue was also found to have significant negative correlations with all five Functioning Scales on the QLQ-C30. Thus, a HNCa survivor's experience of fatigue may not only be associated with decreased QoL, but also decreased functioning in multiple domains. Similarly, insomnia was also found to have a significant negative relationship with QoL, in addition to significant negative relationships with physical, role, and emotional functioning, and positive relationships with fatigue and pain. Therefore, it may be suggested that when a HNCa survivor presents with a single concern (e.g., pain, fatigue or insomnia), there may be many underlying issues (e.g., social, emotional, and/or role dysfunction) that may not be directly apparent. Attending to a survivor's holistic experience of disablement may allow for the identification of individuals who are not forthcoming with psychosocial issues, and yet, are struggling to cope (Carlson & Bultz, 2004). Understanding the synergistic associations between common morbidities faced by HNCa survivors has important implications for short and long-term recovery and cancer rehabilitation. While future research is required to fully elucidate groupings of interrelated symptoms, the identification of biopsychosocial symptom clusters may serve to inform rehabilitation efforts. In turn, these efforts may work to aid survivors' resumption of homeostatic levels of functioning and combat the risk of declines in QoL that occur secondary to the biopsychosocial disablement experience of HNCa.

Symptomology on the EORTC QLQ-H&N35. The QLQ-H&N35 module assesses areas of concern that are specifically tailored to individuals who have been diagnosed with HNCa. As such, relations that may exist with resilience, global QoL, and areas of concern captured by the QLQ-H&N35 that were not captured by the QLQ-C30, which is designed for use in general oncological populations irrespective of disease site, were explored. For instance, the

strong-to-moderate negative correlation between the Teeth Single Item Measure and both resilience and QoL would not have been identified without the use of the QLQ-H&N35. The same can be said for the significant and strong negative relationship found between the Nutritional Supplements Single Item Measure and QoL. Finally, the same applies to the moderately significant negative relationships found between the single item measures pertaining to "feeling ill" and use of pain killers and QoL. The QLQ-H&N35 ultimately identified issues unique to HNCa that had additional relationships with survivors' resilience and QoL. However, in addition to the myriad challenges identified by both the QLQ-C30 and the QLQ-H&N35, demographic characteristics also have potential connections to a HNCa survivor's resilience and QoL. Thus, consideration of demographic characteristics warrants discussion.

Observational Analyses of Demographic Characteristics

As anticipated, given limitations associated with the small sample size (N=31) and the fact that it was a sample of convenience, no statistically significant relationships were observed between resilience and the demographic characteristics of the HNCa survivors that participated. However, observational analyses of the demographic variables that include participant sex, age, site of cancer, clinical stage of cancer, treatment modality, and elapsed time since diagnosis and treatment completion deserves some comment.

Sex. First and foremost, it must be noted that females were substantially underrepresented in the present sample; thus, findings pertaining to resilience, QoL and sex are speculative. Although it cannot be verified statistically, resilience tended to be higher in females than males in the present sample. In light of the significant relationship found between resilience and social functioning, it could be suggested that female participants tended to be more resilient since females tend to seek and receive a higher degree of social support than males which may

augment positive adjustment to disease (Bekes, Beaulieu-Prevost, Guay, Belleville, & Marchand, 2016). In essence, since strong social functioning is associated with resilience, women may benefit from their inclination towards social engagement in coping with challenges.

Conflicting data exist in the literature pertaining to the effects of gender on resilience. For instance, while Pudrovska (2010) did not investigate resilience, it was found that men were more vulnerable to the adverse psychosocial consequences of cancer. However, since a low level of resilience is likely indicative of a high level of vulnerability to psychosocial dysfunction (Markovitz et al., 2015), if resilience had been assessed by Pudrovska (2010), a lower level of resilience may also have been found in males. However, Bonanno, Galea, Bucciarelli, and Vlahov (2007), as well as Cohen, Bazilianski, and Beny (2013) reported that resilience tends to be lower in females compared to males. Neither Bonanno et al. (2007) or Cohen et al. (2013) offered insights into the reasons why the male sex was correlated with increased resilience. Clearly, the moderating effects of gender on resilience warrants future research.

Age. The present study found negligible changes in the level of resilience in HNCa survivors with increasing participant age. This finding suggests that one's capacity for resilience does not depend on age. However, published research literature suggests multiple conflicting explanations for the impact of age on resilience. For instance, the accumulation of adversities in addition to the effects of physical and cognitive decline and loss of personal resources that occurs with increasing age, may in turn, weaken resilience (Cohen et al., 2013). More optimistically, resilience may be strengthened with increasing age as a result of gained experience and enhancement of efficient coping strategies that accompanies increased encounters with challenging situations (Brandtstadter, 1999).

Relative to individuals with cancer, Cohen et al. (2013) found that resilience increased with age in their sample of individuals with colorectal cancer. However, in light of the multiple explanations of the effects of age on resilience that exist in the literature, additional research is needed to further investigate this potential relationship in those with HNCa. Additionally, contrary to the general consensus of QoL literature which suggests that older individuals exhibit better QoL following treatment for HNCa (Pandey, Devi, Ramdas, Krishnan, & Kumar, 2009), the present study found that QoL tended to be lower in older HNCa survivors. This conflicting result may simply be explained by the small sample of convenience utilized in the present study.

Site of HNCa, clinical stage, and treatment modality. The sample size of the present study was small, which meant that when it was divided into subcategories within HNCa site, stage, and treatment modality, the subgroups were even smaller. As such, no clearly discernable trends were apparent through observational analyses. The apparent lack of marked difference between the subgroups within the site, stage, and treatment modality data, would suggest that these three demographic variables have no impact on resilience and QoL. Although no clear trends were identified, it is conceivable that certain outcomes associated with the various categorical subgroups (e.g., later staged cancer, total laryngeal deletion) within each of these three variables may pose different challenges that may oppose an individual's ability to be resilient or threaten QoL. While limited data on the impact of HNCa site and treatment modality on resilience exists, the present findings pertaining to stage of cancer was consistent with a study of resilience in individuals with colorectal cancer (Cohen et al., 2013). Although site and treatment modality were not considered, no association was found between resilience and stage of cancer in individuals with colorectal cancer (Cohen et al., 2013).

Time since diagnosis and completion of treatment. Graphical representations of resilience and time since diagnosis and treatment completion revealed a slight increase in resilience with increasing time. However, substantial variation was observed. Additionally, graphical representations of QoL and time since diagnosis and treatment completion also display a substantial amount of variability. Although strictly speculative, given this variability in resilience and QoL with time since diagnosis and treatment, it may be suggested that the idiosyncratic interaction of protective and risk factors augment the influence of passing time to further impact one's level of resilience and, hypothetically, the ameliorating influence of resilience on a HNCa survivor's perceived QoL. Although data on the influence of time since diagnosis and treatment of cancer is limited in the resilience literature, Sharpley, Wooten, Bitsika, and Christie (2013) found substantial variability in resilience over time in individuals diagnosed with prostate cancer. Their findings, as well as those of the present study suggest that resilience may not follow a clear-cut pattern, but instead resembles a fluid trajectory that is highly individualized and may ebb and flow as time passes.

Since the participants' demographic characteristics did not serve to clarify the high level of resilience identified in this sample, the previously stated relationships between various aspects of functioning and symptomology associated with the disablement experience of HNCa may provide a more perceptive understanding of the factors related to the presence of resilience in survivors of HNCa.

Limitations of the Current Study

Limitations of the present study must be acknowledged. To begin, several methodological limitations existed relative to data acquisition. Data were collected solely from one tertiary care institution and, thus, the generalizability of the present results to individuals

diagnosed and treated in different institutions may be limited. Furthermore, because this was a sample of convenience, assumptions cannot be made about the resilience and QoL of individuals who chose not to participate. As is the case with most studies involving clinical populations, the current findings are based on a small sample size (N=31). Thus, causal conclusions relative to the present findings on resilience and QoL in HNCa survivors cannot be drawn definitively and external validity concerns must be acknowledged.

More specifically, concerns pertaining to external validity are directed to the representativeness of the present sample of HNCa survivors. The present sample may not provide a fully representative indication of the whole population of individuals who have been diagnosed with and treated for HNCa. For instance, while the sample depicted in the current study only included two participants diagnosed with thyroid cancer, The Canadian Cancer Society (2017) reported that thyroid cancer has the highest incidence among all HNCa diagnoses. Further, the high representation of oral cavity cancer and laryngeal cancer in the present sample reflect the fact that these two cancers have the second and third highest incidences among all HNCa sites (Canadian Cancer Society, 2017). However, some common groupings within the larger HNCa category were substantially underrepresented in the present sample since there was only one participant diagnosed with nasopharyngeal cancer and none diagnosed with oropharyngeal or hypopharyngeal cancers. Thus, although the present study found that HNCa survivors tended to be highly resilient, due to external validity concerns, generalizability of the present data to others with HNCa should be done with caution.

Due to the exploratory nature of the present study, inclusion criteria allowed for substantial demographic variability (i.e., sex, age, site and stage of cancer, treatment modality, and time since diagnosis and treatment). As a result, there was considerable skew in the results

which further limits potential conclusions related to mediating or moderating factors that may influence measures of resilience or QoL. Finally, data were collected at a single point in time. Therefore, the results of these data do not portray the potentially fluid nature of resilience and perceived QoL throughout the HNCa survivorship experience. However, despite the noted limitations, the present data may provide insights into variables of interest that can be explored in the future.

Clinical Implications

From a clinical perspective, several implications arise from the findings of the present study that not only suggest that remarkable resilience is exhibited by HNCa survivors, but also that a significant relationship exists between their resilience and QoL. A range of clinically meaningful implications may exist for the construct of resilience that pertain to the minimization of the impact of HNCa and the maximization of QoL. Nonetheless, the presence of resilience must first be identified. As such, screening for resilience may present as an opportunity for early identification of individuals with lower levels of resilience and, thus, potentially higher vulnerability for the development of psychosocial challenges (Markovitz et al., 2015). Following identification of those that are more vulnerable to the impact of psychosocial challenges, referrals may be made to allied healthcare providers who may work to support psychosocial adjustment and, thereby, minimize the impact of the disease and treatment. By proactively offering vulnerable patients support for psychosocial disablement, the confounding nature of interrelated biopsychosocial symptom clusters may be diminished. Thus, not only does screening for resilience provide the opportunity for the provision of increased support with psychosocial adjustment, it also works to optimize the delivery of biologically focused care.

The results of the present study are viewed to justify screening for resilience in individuals who have been diagnosed with HNCa, however, it is suggested that compassion should guide the timing of resilience screening. For instance, at the time of initial diagnosis, patients may be overwhelmed with emotionally charged information. As such, compassionate consideration of the timing of resiliency screening may be in the best interest of the patient and may also ensure an accurate result is obtained from the screen. In light of these considerations, it suggested that future research be conducted to investigate the efficacy and validity of providing a resilience measurement instrument, such as the CD-RISC, to the patient's significant other. Using a significant other as a proxy to index the resilience of the patient may serve to reduce the demands on the patient at a potentially intense time of both physical and psychological challenge.

The clinical implications for minimizing the psychosocial challenges of HNCa may also lay in potential interventions aimed at fostering and increasing individuals' resilience. While the efficacy of potential interventions that nurture resilience has not yet been studied in HNCa survivorship populations, the virtue of such interventions would be of significance given that resilience is malleable and amenable to nurturance and training (Tian & Hong, 2014). Through interventions that foster resilience, patient well-being may be promoted (Loprinzi et al., 2011). Studies of resilience training interventions in other oncological populations have shown considerable promise. For instance, Loprinzi et al. (2011) assessed the effect of a resiliency training program in a sample of individuals previously diagnosed with breast cancer. The findings of their study demonstrated a significant improvement in resilience, as well as reduced anxiety and improved overall QoL following the training program. The feasibility and efficacy of interventions that foster resilience was also demonstrated in a study by Sharpley et al. (2013) in

which it was found that resilience could be fostered to decrease depression in individuals with prostate cancer. Ultimately, the screening and identification of individuals who are at a heightened risk for the development of psychosocial disablement, allows them to be directed towards interventions before psychosocial morbidity is firmly manifested. In turn, interventions that foster resilience proactively bolster individuals' capacity to rebound from any current or future psychosocial challenges.

Therefore, proactive consideration and enhancement of positive psychosocial factors, namely resilience, may have a role in clinical practice that is just as critical as minimizing the negative risk factors (e.g., concerning symptoms, long-term and late effects) faced by HNCa survivors (Li & Wang, 2016). In light of findings of the present study, it is suggested that interventions that work to enhance resilience may ultimately augment efforts to reduce the negative biopsychosocial risk factors associated with HNCa. Therefore, further research should aim to investigate the efficacy of resilience-enhancing interventions in HNCa survivors and the potential for such interventions to have the secondary effect of minimizing the biopsychosocial consequences of HNCa and maximizing QoL. Ultimately, clinically meaningful short- and long-term outcomes may be promoted by interventions that promote and foster resilience in those individuals identified to be less resilient and, thus, at a heightened risk of developing psychosocial morbidity. By fostering resilience HNCa survivors QoL may be maximized and the impact of the disease may be minimized.

Directions for Future Research

The findings of the present study provide an initial foundation from which future research can build a holistic and comprehensive understanding of resilience and its relationship with QoL in HNCa survivors. It is recommended that future research explore the trajectory of resilience

throughout the clinical pathway of HNCa treatment and into the phases of long-term survivorship. To accomplish this objective, a prospective longitudinal design is suggested to elucidate how resilience changes over time and relative to certain events that occur throughout the clinical pathway and survivorship. Furthermore, simultaneous comparison of the trajectory of QoL may serve to clarify the nature of the relationship between resilience and QoL. It is recognized that variability may exist given the rapid changes in myriad variables and challenges from time of diagnosis to completion of treatment and beyond into extended survivorship. By delineating the course and process of resilience and the potential implications on QoL, recommendations that guide the timing of proactive interventions pertaining to resilience in individuals with HNCa may be designed and implemented. For instance, it is recommended that future research investigate how and when the prophylactic intent of resilience enhancing interventions may be optimized through insight into the pattern of resilience. Understanding the trajectory of resilience may serve to predict when the level of resilience may be lowest and, thus, when individuals may be at a heightened risk for psychosocial disablement and detriments to QoL. Furthermore, future research that delineates the trajectory of resilience in the specific context of various subgroups of HNCa, may elicit data relative to potential predictors that are unique to the HNCa disablement experience and that serve to influence the individual's capacity for resilience.

Previous research that has investigated predictors of adult resilience has been limited to idiosyncratic person-centered factors (e.g., optimism, hardiness) (Bonanno et al., 2007). Thus, it is recommended that future research seeks to identify potential contextual factors specific to the adverse circumstances of the survivorship experience of HNCa that may serve as predictors of adult resilience. Resilience is not borne of adversity but rather, emerges within the context of

adverse circumstances. Therefore, understanding the specific HNCa related factors that may interact with and influence the well-documented developmental factors of resilience that originate during childhood, may help to guide the targets of HNCa specific resilience enhancing interventions in adult survivors. Ultimately, given the benevolent influence of resilience on QoL in cancer survivors in general and HNCa survivors in specific, further research may provide valuable information that may expand knowledge of the potential impact of resilience on outcomes.

Conclusions

In summary, resilience was found to be present in the current sample of HNCa survivors. The identification of resilience in individuals who had completed treatment for HNCa suggests that positive adaptation is possible following the potentially disabling experience of the disease and its treatment. The HNCa disablement experience has the potential to exert a profound impact on survivors' physical, psychological, and social functioning (Bornbaum et al., 2012). In turn, profound biopsychosocial challenges associated with HNCa and its treatment have the potential to reduce one's QoL. In the context of the HNCa disablement experience, the present study also identified a relationship between resilience and QoL. As such, resilience may play a central role in reducing or ameliorating the negative influence of the HNCa disablement experience on QoL.

Due to advancements in treatment efficacy, cancer survival rates are increasing (Giuliani et al., 2016; Stanton et al., 2015; Wells et al., 2015). As such, there is an increasing number of individuals who must face the potentially disabling biopsychosocial consequences of HNCa and diminished QoL. With the rising rate of survivorship comes the need to address the consequences commonly faced by survivors, or better yet, identify those who are vulnerable to falling victim to the impact of the biopsychosocial consequences of the disease and its treatment.

It is suggested that screening for resilience and identifying vulnerable individuals, may present as a proactive approach that serves to minimize the influence of challenges faced by survivors. Given the disabling impact of these challenges on QoL, interventions that foster resilience may facilitate not only the minimization of the impact of the disease, but also the maximization of QoL. Thus, the importance of resilience in HNCa survivors cannot be understated. Finally, given the growing number of HNCa survivors who must take up citizenship in the "remission society" (Frank, 1995, p. 8), there is a great need to proactively address the complex issues faced by those who are no longer "sick", but remain plagued by the consequences of their illness. Ultimately, resilience may guide citizens of the remission society away from the kingdom of the sick and aid in the renewal of their passport to the kingdom of the well.

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APPENDIX A

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice

Principal Investigator: Dr. Philip Doyle
Department & Institution: Health Sciences/Communication Sciences & Disorders, Western University

Review Type: Delegated
HSREB File Number: 108785
Study Title: An exploration of resilience in individuals treated for head and neck cancer

HSREB Initial Approval Date: March 02, 2017
HSREB Expiry Date: March 02, 2018

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Western University Protocol	Received February 22, 2017	
Revised Letter of Information & Consent		2017/02/28
Data Collection Form/Case Report Form	Demographic Information Survey	2017/02/22
Instruments	EORTC QLQ-HN35	
Instruments	EORTC QLQ-C30	
Instruments	Connor-Davidson Resilience Scale (CD-RISC-25)	2015/01/01
Other	References for Section 2.1	
Other	Support Services Information for Participants	

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

APPENDIX B

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Amendment Approval Notice

Principal Investigator: Dr. Philip Doyle
Department & Institution: Health Sciences\Communication Sciences & Disorders,Western University

Review Type: Delegated
HSREB File Number: 108785
Study Title: An exploration of resilience in individuals treated for head and neck cancer

HSREB Amendment Approval Date: March 13, 2017
HSREB Expiry Date: March 02, 2018

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Letter of Information & Consent		2017/03/09

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the amendment to the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

APPENDIX C

An Exploration of Resilience in Individuals Treated for Head and Neck Cancer

Rehabilitation Sciences
Western University

Letter of Information

Principal Investigators: Philip C. Doyle, Ph.D. & Chelsea MacDonald, B.H.Sc.

Introduction

You are being invited to participate in a research study exploring resilience and quality of life among individuals who have completed treatment for head and neck cancer. The term resilience refers to how individuals respond to challenges in their lives and ultimately how they bounce back in the face of such challenges. Resilience may define how individuals reestablish a "sense of balance" in their daily living. Your participation is requested because you have been diagnosed with head and neck cancer, and are between one month and five years beyond the completion of treatment. This study seeks to understand how resilience may have influenced your quality of life in the context of your experience of surviving head and neck cancer.

The purpose of this letter is to provide you with the information you require to make an informed decision regarding your participation in this research study. This letter contains information to aid in your decision of whether or not to participate in this research. It is important that you understand the rationale for why this study is being conducted and what your participation will involve. Please take your time to read this letter and feel free to ask any questions to ensure your understanding is complete. You will be given a copy of this letter to keep for your records.

Purpose of Study

The purpose of this research study is to investigate the influence of resilience on the quality of life of individuals who have completed treatment for head and neck cancer. This study is being conducted to explore the potential for resilience to play a role in buffering the influence of the adverse experience of head and neck cancer and its treatment on your quality of life. The primary aim of the present study centres on the identification and description of resilience in individuals who have completed treatment for head and neck cancer. The identification of resilience may initiate acknowledgement of its value in acting as a potential protective factor that may reduce the impact of head and neck cancer on one's quality of life.

This study represents a portion of a master's thesis project for one of the investigators (C.M.).

Activities of Participation

If you agree to participate in this research, you will receive a package of materials that will allow for the collection of data to investigate resilience and its potential role in reducing the negative effect of head and neck cancer on quality of life. Enclosed in your package will be a demographic information inquiry form, and three questionnaires pertaining to resilience and quality of life in relation to your cancer experience. The questionnaires you will be asked to complete in your package include the Connor-Davidson Resilience Scale (CD-RISC) to gather data pertaining to resilience, the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), and the European Organization for Research and Treatment of Cancer Head and Neck Cancer Module (EORTC QLQ-H&N35) to gather information regarding your quality of life. The completion of these materials is estimated to take approximately 20 minutes. You may complete the package of materials at the time you consent to participate, or take it home and return it by mail at a later date. A prepaid and pre-addressed envelope for the return of the package of materials will be provided if you choose to complete the study package off site.

Please note that you will not be compensated for your participation in this research study.

Inclusion and Exclusion Criteria

Inclusion Criteria

Your participation in this study is based on your diagnosis of head and neck cancer, as well as your completion of any type of treatment. Participation is limited to individuals who are a minimum of one month, but no more than five years beyond the completion of treatment. You must be between the ages of 25 and 85. Participants must display adequate English proficiency required for informed consent to be obtained and the completion of the package of study materials.

Exclusion Criteria

Exclusion from participation in this study may be based on an individual's previous diagnosis of another cancer regardless of its location. Individuals that have been diagnosed and treated for skin cancer in the head and neck region will not be permitted to participate. Cancer treatment that is ongoing will also exclude individuals from participation.

Possible Benefits and Risks Involved in Participation

Possible Benefits

You are unlikely to directly benefit as a result of your participation in this research study. However, a better understanding and awareness of factors that may affect resiliency and quality of life may be gained from your participation. At a societal level, data collected through this study may provide health care practitioners with information regarding the value of screening for

resilience in order to identify individuals with low levels of resilience and thus, higher vulnerability to the influence of negative consequences associated with head and neck cancer.

Possible Risks

There are no foreseeable risks or discomforts associated with your participation in this research study. However, you will be asked to complete questionnaires that may delve into sensitive topics pertaining to your resilience and quality of life. Consequently, you may experience negative emotions. If this occurs, it is requested that you contact your physician, or a member of the research team should you require help managing these negative emotions. Additionally, a contact list for local psychological support services and organizations that offer support to individuals that have experienced head and neck cancer is included in the package of study materials.

Voluntary Participation

Your participation in this research study is entirely voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no negative consequences. You do not waive any legal rights by signing the consent form. Making the decision not to participate in this study will have no impact on your future health care.

Confidentiality

All data collected in this study will remain confidential. Personally identifying information will not be retained. All data will be kept in a secure locked location at Western University. If the results of this study are published, no information that could disclose your identity will be used. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study related records to monitor the conduct of the research.

Contacts for Further Questions

If you require further information regarding this research study or additional questions arise in relation to your participation in this study, please feel free to contact:

Philip C. Doyle, Ph.D. or Chelsea MacDonald, B.H.Sc.
Laboratory for Well-Being and Quality of Life in Oncology
Health and Rehabilitation Sciences

If you have any questions about the conduct of this study or your rights as a research subject, you may contact:

Office of Human Research Ethics

Rehabilitation Sciences
Western University

Letter of Consent

Study Title: An Exploration of Resilience in Individuals Treated for Head and Neck Cancer

Principal Investigators: Philip C. Doyle, Ph.D. & Chelsea MacDonald, B.H.Sc.

I have read the *Letter of Information,* have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

_____

Participant's Name *(Printed)*

_____ _____

Participant's Signature Date (dd/mm/yyyy)

_____ _____

Signature of Person Obtaining Consent Date (dd/mm/yyyy)

APPENDIX D

Demographic Information Survey

Title: An Exploration of Resilience in Individuals Treated for Head and Neck Cancer

Study Investigators: Philip C. Doyle, Ph.D. & Chelsea MacDonald, B.H.Sc.

Please read the following questions carefully and provide answers as accurately as possible. For multiple choice options, please circle all choices that apply to you. If no suitable options exist, please use the space provided to explain. Also, if there is any additional information that you feel is important to report please use the back of these pages to include it.

Sex: M / F / Other

Year of Birth: _____ Month of Birth: _____

Number of months since your diagnosis: _____

Number of months since treatment completion: _____

Site of Cancer:

a) Oral cavity (e.g., lip, tongue, cheek, tonsil, etc.)
b) Larynx (voice box)
c) Throat (e.g., pharynx, hypopharynx, oropharynx)
d) Thyroid
e) Sinuses/Paranasal sinuses
f) Other

If "other", please specify:
_____

Method of Treatment:

a) Surgery
b) Radiation therapy
c) Chemotherapy
d) Chemoradiation therapy
e) Other

If "other", please specify:
_____

Marital Status (circle one):

a) Married
b) Separated
c) Divorced
d) Widowed
e) Common-law
f) Engaged
g) Single
h) Other

If "other", please specify:

_____

Occupational Status:

a) Currently working – full-time
b) Currently working – part-time
c) Volunteer
d) Retired
e) Other

If "other", please specify:

_____

Highest Level of Education Achieved:

a) Completed High school
b) Completed College
c) Undergraduate University degree
d) Post-graduate University degree
e) Other

If "other", please specify:

_____

Household income (optional):

(a) Less than $25, 000
(b) $25, 000 - $40, 000
(c) $40, 001 - $55, 000
(d) $55, 001 - $70, 000
(e) $70, 001 - $85, 000
(f) Greater than $85, 000
(g) Would prefer not to say

Please feel free to include any additional information that you feel is important specific to this project in the space provided below or on the opposite side of this document. Thank you.

_____
_____
_____
_____

APPENDIX E

Connor-Davidson Resilience Scale 25 (CD-RISC-25) ©

initials ☐☐☐ *ID#* ☐☐☐☐☐☐☐ *date* ☐☐/☐☐/☐☐☐☐ *visit* ☐☐ *age* ☐☐

For each item, please mark an "x" in the box below that best indicates how much you agree with the following statements as they apply to you over the last month. If a particular situation has not occurred recently, answer according to how you think you would have felt.

		not true at all (0)	rarely true (1)	sometimes true (2)	often true (3)	true nearly all the time (4)
1.	I am able to adapt when changes occur.	☐	☐	☐	☐	☐
2.	I have at least one close and secure relationship that helps me when I am stressed.	☐	☐	☐	☐	☐
3.	When there are no clear solutions to my problems, sometimes fate or God can help.	☐	☐	☐	☐	☐
4.	I can deal with whatever comes my way.	☐	☐	☐	☐	☐
5.	Past successes give me confidence in dealing with new challenges and difficulties.	☐	☐	☐	☐	☐
6.	I try to see the humorous side of things when I am faced with problems.	☐	☐	☐	☐	☐
7.	Having to cope with stress can make me stronger.	☐	☐	☐	☐	☐
8.	I tend to bounce back after illness, injury, or other hardships.	☐	☐	☐	☐	☐
9.	Good or bad, I believe that most things happen for a reason.	☐	☐	☐	☐	☐
10.	I give my best effort no matter what the outcome may be.	☐	☐	☐	☐	☐
11.	I believe I can achieve my goals, even if there are obstacles.	☐	☐	☐	☐	☐
12.	Even when things look hopeless, I don't give up.	☐	☐	☐	☐	☐
13.	During times of stress/crisis, I know where to turn for help.	☐	☐	☐	☐	☐
14.	Under pressure, I stay focused and think clearly.	☐	☐	☐	☐	☐
15.	I prefer to take the lead in solving problems rather than letting others make all the decisions.	☐	☐	☐	☐	☐
16.	I am not easily discouraged by failure.	☐	☐	☐	☐	☐
17.	I think of myself as a strong person when dealing with life's challenges and difficulties.	☐	☐	☐	☐	☐
18.	I can make unpopular or difficult decisions that affect other people, if it is necessary.	☐	☐	☐	☐	☐
19.	I am able to handle unpleasant or painful feelings like sadness, fear, and anger.	☐	☐	☐	☐	☐
20.	In dealing with life's problems, sometimes you have to act on a hunch without knowing why.	☐	☐	☐	☐	☐
21.	I have a strong sense of purpose in life.	☐	☐	☐	☐	☐
22.	I feel in control of my life.	☐	☐	☐	☐	☐
23.	I like challenges.	☐	☐	☐	☐	☐
24.	I work to attain my goals no matter what roadblocks I encounter along the way.	☐	☐	☐	☐	☐
25.	I take pride in my achievements.	☐	☐	☐	☐	☐

01-01-15

APPENDIX F

ENGLISH

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ____
Your birthdate (Day, Month, Year): ____
Today's date (Day, Month, Year): 31 ____

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

ENGLISH

During the past week:	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

APPENDIX G

EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	Not at all	A little	Quite a bit	Very much
31. Have you had pain in your mouth?	1	2	3	4
32. Have you had pain in your jaw?	1	2	3	4
33. Have you had soreness in your mouth?	1	2	3	4
34. Have you had a painful throat?	1	2	3	4
35. Have you had problems swallowing liquids?	1	2	3	4
36. Have you had problems swallowing pureed food?	1	2	3	4
37. Have you had problems swallowing solid food?	1	2	3	4
38. Have you choked when swallowing?	1	2	3	4
39. Have you had problems with your teeth?	1	2	3	4
40. Have you had problems opening your mouth wide?	1	2	3	4
41. Have you had a dry mouth?	1	2	3	4
42. Have you had sticky saliva?	1	2	3	4
43. Have you had problems with your sense of smell?	1	2	3	4
44. Have you had problems with your sense of taste?	1	2	3	4
45. Have you coughed?	1	2	3	4
46. Have you been hoarse?	1	2	3	4
47. Have you felt ill?	1	2	3	4
48. Has your appearance bothered you?	1	2	3	4

Please go on to the next page

During the past week:		Not at all	A little	Quite a bit	Very much
49.	Have you had trouble eating?	1	2	3	4
50.	Have you had trouble eating in front of your family?	1	2	3	4
51.	Have you had trouble eating in front of other people?	1	2	3	4
52.	Have you had trouble enjoying your meals?	1	2	3	4
53.	Have you had trouble talking to other people?	1	2	3	4
54.	Have you had trouble talking on the telephone?	1	2	3	4
55.	Have you had trouble having social contact with your family?	1	2	3	4
56.	Have you had trouble having social contact with friends?	1	2	3	4
57.	Have you had trouble going out in public?	1	2	3	4
58.	Have you had trouble having physical contact with family or friends?	1	2	3	4
59.	Have you felt less interest in sex?	1	2	3	4
60.	Have you felt less sexual enjoyment?	1	2	3	4

During the past week:		No	Yes
61.	Have you used pain-killers?	1	2
62.	Have you taken any nutritional supplements (excluding vitamins)?	1	2
63.	Have you used a feeding tube?	1	2
64.	Have you lost weight?	1	2
65.	Have you gained weight?	1	2

APPENDIX H

Scoring Procedure for EORTC QLQ-C30 and EORTC QLQ-H&N35

Summary of scoring procedure:

1. Estimate the average of the items that contribute to the scale; this is the *raw score*.
2. Use a linear transformation to standardize the raw score, so that scores range from 0 to 100; this is the *scale score.*

Example:

If items I_1, I_2, ... I_n, are included in a scale, the scoring procedure is as follows:

1. Raw score calculation

$$RawScore = RS = (I_1 + I_2 + \ldots + I_n) / n$$

2. Linear transformation

For Functional Scales: $S = \left\{1 - \frac{RS-1}{range}\right\} \times 100$

Symptom Scales/Single Item Measures: $S = \left\{\frac{(RS-1)}{range}\right\} \times 100$

Global Health Status/QoL: $S = \left\{\frac{(RS-1)}{range}\right\} \times 100$

Where *range* is the difference between the maximum and minimum *RS* values.

Adapted from: Fayers, P. M., Aaronson, N. K., Bjordal, K., Groenvold, M., Curran, D., & Bottomley, A. (2001). *The EORTC QLQ-C30 scoring manual* (3rd ed.). Brussels: European Organisation for Research and Treatment of Cancer.

CURRICULUM VITAE

CHELSEA MACDONALD

EDUCATION

2015-2017(antic.) **Master of Science Candidate,** Health and Rehabilitation Sciences, Rehabilitation Science

Western University, London, Ontario

2011-2015 **Bachelor of Health Science**, Honors Specialization in Health Sciences

Western University, London, Ontario

· Dean's Honor List

2007-2011 **Ontario Secondary School Diploma**

Centennial Collegiate Vocational Institute, Guelph, Ontario

· Ontario Scholar

RESEARCH EXPERIENCE

2017(antic.) Master of Science Degree, *Western University*

· A master's research project was conducted in the Laboratory for Well-Being and Quality of Life in Oncology under the supervision of Dr. Philip Doyle.

2016 Research Coordinator, *Parkwood Institute*

· Acted as the Research Coordinator for a prospective cohort study titled: The impact of cognition and anxiety on falls and reintegration back into community living in older adults after discharge from inpatient rehabilitation for a lower extremity amputation.

· Assisted in data collection through the administration of five assessments pertaining to quality of life, body image, prostheses use, depression and anxiety.

2015 Independent Study, *Western University*

· Under the supervision of Dr. Philip Doyle, issues related to caregiver burden concomitant with caring for individuals with acquired disorders of speech and language were researched. The primary population of interest pertained to the caregivers of individuals who experience communication disorders secondary to stroke.

EMPLOYMENT

2011-2017 **Medical Office Administrative Assistant**, *East Wellington Family Health Team*

Rockwood, Ontario

- Worked to support the clinic's team of nine doctors and ten nurses. Responsibilities included data entry and maintenance of the clinic's Electronic Medical Records (EMR). These tasks were carried out successfully and effectively with minimal supervision. Self-motivation and responsibility were essential to attain the accuracy and timeliness demanded by this position.
- Worked closely with the doctors on SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms) coding within the EMR. Codes were assigned to diagnoses to allow the EMR to automatically check for possible contraindications of prescribed medications for the coded diagnoses.

2015-2016 **Teaching Assistant**, *Western University*

London, Ontario

- Held a teaching assistantship position for Health Issues in Childhood and Adolescence (HS2700a) in the fall semesters of 2015 and 2016.
- Independently organized and conducted one hour long tutorials two times per week for 80 second year undergraduate students, during which various teaching strategies were employed to enrich the students' learning experience. Such strategies included facilitated small group time, larger group discussions and lecture based instruction.
- Marked and provided feedback for weekly written assignments.

VOLUNTEER EXPERIENCE & COMMUNITY INVOLVEMENT

2014 **Volunteer with Older Adults**, *Homewood Health Centre*

Guelph, Ontario

- Assisted older adult inpatients during their meal time at the Homewood Health Centre, an interdisciplinary mental health facility. The patients ranged in independence and severity of mental health symptoms.
- Considerable time was spent assisting non-verbal Alzheimer's patients who required additional assistance during meal times. The establishment

of a shared understanding and mutual respect was essential in order to facilitate a smooth meal time routine.

2014 - 2015 **Member of Alzheimer's Western Club**

Western University, London, Ontario

ACADEMIC HONORS, AWARDS & SCHOLARSHIPS

2015 - 2017 Western Graduate Research Scholarship

2013 - 2015 Dean's Honor List

2011 The Western Scholarship of Excellence

· Awarded to students with a final admission average between 90-94%.

2011 Centennial Collegiate Vocational Institute Staff Scholarship

· Presented on the basis of scholarship and qualities of character to a student that is continuing their education at the post-secondary level.

2011 Centennial Collegiate Vocational Institute Spartan Award

· Given to a student in recognition of exceptional academic achievement in addition to outstanding extracurricular involvement.

2011 Ontario Scholar

· Awarded for the attainment of an average of 80% and above in grade 12.